

# **TOWARDS AN UNDERSTANDING OF PROFOUND MENTAL HANDICAP**

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## ABSTRACT

A brief introduction to profound mental handicap (PMH) is given. Problems in identifying the population to be studied are described, and detailed criteria, based upon behavioural characteristics, are proposed. A comprehensive survey of research literature relevant to people with profound mental handicap is presented, and inadequacies discussed. Frameworks within which to place the behaviour of the profoundly mentally handicapped are also discussed, and a modified developmental framework is suggested. An argument is made for the usefulness of conducting research which is informed by mother-infant studies and which examines the naturally occurring behaviour of the profoundly mentally handicapped, paying particular attention to communicative and emotional characteristics.

The behaviour of a representative sample of 66 people with profound handicap, living at home or in one of three institutions, is investigated using micro-analysis of filmed sessions between carer and subject, and information gathered from two oral questionnaires administered to carers. A reliable profile of the behavioural characteristics of this sample of people with profound handicap is therefore obtained.

Important findings include: a high level of awareness and engagement to the carer indicating a general responsiveness amongst people with profound handicap to aspects of the environment, and the ability to communicate with other people; evidence of a wide variety of social and emotional behaviours, in particular a discriminating sense of humour; evidence of spontaneous learning; and the presence of a 'responsiveness' factor underlying the behaviour of people with profound handicap, and dividing the subjects into distinct subgroups.

The implications of these findings for the day-to-day care of people with profound handicap, and for an improved understanding of the nature of profound mental handicap are discussed.

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"God has scattered among us, rare as  
the possessors of genius, the *idiot*...  
in order to bind the rich to the needy,  
the talented to the incapable,  
all men to each other."

Edouard Seguin (1812-1880)

## CHAPTER 1. INTRODUCTION

### 1. People with a Profound Mental Handicap

People with a profound mental handicap (PMH) do not make up a large part of our society and the majority of us probably live our lives without ever meeting someone with a profound handicap. They are a group of people who are unable to care for themselves and who will always, to a large extent, remain so. Morally, they are the responsibility of all of us who are able to be independent.

There have been people with a mental handicap - and people with a profound mental handicap - for as long as there have been people, but their treatment has varied greatly. X-rays of Egyptian mummies have revealed skeletal anomalies associated with mental handicap; in Classical times, many states (Sparta, for example) actively promoted infanticide of infants seen to be handicapped at birth (which, since they are more conspicuous, would probably mean all persons with profound handicap), or else tolerated them as figures of amusement - a tradition which has continued until quite modern times. In more recent history, infanticide of people with profound handicap was again taken up in Nazi Germany. Interestingly, this contrasts with what is our oldest evidence of people with handicap, the discovery in southern Czechoslovakia by Dr. Bohuslav Klima of a very physically deformed adult female skeleton approximately 26,000 years old, buried alongside two non-handicapped adults (Bahn, 1988). We do not know the degree of this woman's handicap, but she suffered from scoliosis of the vertebral column and immature limb development, her skull was strikingly asymmetrical and perforated, and she most probably had encephalitis as a child. The fact that she reached adulthood is remarkable. She certainly would not have been able to fend for herself, so the implication is that other more able people cared for her, which, at a time when food was scarce, must have been a considerable burden. In fact, it is now established in Archaeology that middle and upper paleolithic communities took good care of - possibly special care of - their handicapped members.

Modern approaches have perhaps come full circle. There is a growing awareness that it is a moral duty to provide appropriate care or support for people with a mental handicap, and this is coupled with an awareness of the cost of doing it right. Community care - the resettlement of long term mentally handicapped hospital residents into the community - is at present the avowed aim of all Health Authorities in



Britain. It has had a controversial history, with little agreement on the needs of a resident leaving hospital or how best to meet them. The care of people with a profound handicap, however, adds a completely new dimension to the problem: put simply, it is inconceivable that any person with a profound handicap will ever be able to become truly independent of carers. In an era of community care policies people with a profound handicap represent the greatest challenge.

Nor should we forget those that are already living in the community, with their families. For the most part, these families receive whatever support is available for mental handicap in their area. Not enough has yet been discovered of the special needs of a family with a member who has a profound handicap. For this to change, and for community care to work, there is still much to learn about what people with a profound handicap are like as a group and how best to care for them.

What are people with a profound handicap like? Extraordinary as it may seem, there is still a lack of basic knowledge about this group. In fact, even reaching an accepted definition of profound mental handicap can be a major problem. Nevertheless, the term 'profound mental handicap' is widely used and is applied to the least able of the population of people with a mental handicap. A reliable estimate is that the prevalence of profound handicap is around 1/1000 (Fryers, 1984).

Perhaps the most popular view of a person with a profound handicap is of someone with a complete lack of any recognizable mental abilities, receiving constant and total care to keep them alive. They are unpredictable and unable to comprehend anything around them. This tends to be the view of those who have had no experience of profound mental handicap

Talking to parents or experienced carers, however, it becomes clear that there is another view of people with a profound handicap - one that sees them as a collection of individuals, some more able than others, some with striking abilities, some with additional handicaps. Gradually, the stereotype in the first view fades and is replaced by a picture of a group with an occasionally keen, if limited, awareness, a wide variety of abilities, and differing personalities.

Is this reflected in the literature? Despite a surge of interest in recent years, profound mental handicap is still the most poorly understood, least studied area of mental handicap. Nevertheless, it has become the focus of attention, mainly as a result

of the changes in the law in the last two decades which saw people with a profound handicap gain rights in Britain and the United States to an education provided by the state and a 'normal' environment in which to live. This attention has resulted in a substantial increase in our knowledge.

Thus Stainback and Stainback (1983), reviewing the educability of people with a profound handicap, point to a large number of successful training programmes that have used as subjects individuals with a wide range of learning characteristics. Similarly, Rawlings (1985a,b) and Felce et al (Felce, de-Kock, Thomas and Saxby, 1986), amongst others, have shown that improvements in behaviour of people with a profound handicap (including engagement to staff) follow a move out of a large institution to a smaller home. But are experts agreed on the characteristics and the potential of people with a profound handicap? Contrast these findings with the following quotation:

"The existence of the most severely mentally handicapped patient is merely vegetative. The patient is mute, completely helpless and lies in his cot showing no awareness of his surroundings, doubly incontinent, and throughout his life requires the same nursing attention as a small baby."

You could be forgiven for imagining that this quotation dates from sometime before the mid 1950's. In fact, it comes from a textbook on mental handicap published in 1984 (Heaton-Ward and Wiley, 1984, p.69). Clearly, the stereotype is a long time fading.

The point, then, is that despite the increase in research on people with a profound handicap, there are still large areas of confusion or ignorance. One aspect of this is the concentration in research upon the application of behaviour modification studies. In the last fifteen years, Psychological Abstracts lists over six hundred studies which involved subjects with profound handicap, almost half of which were behaviour modification studies. These studies have added much to our practical knowledge of techniques for educating people with a profound handicap, but the danger is that this knowledge will be useless if it is not accompanied by an increase in our understanding of what people with a profound handicap are actually like. In particular, there is a tendency to look at communication or emotional aspects only when they are dependant variables in a behaviour modification experiment - an unnatural and artificially maintained situation.



Fryers (1984) has described with optimism the progress in many areas of research into profound mental handicap. Behaviour modification techniques have been refined; decreasing numbers of children with profound handicap are being born into the community; some potential causes of profound handicap are now treatable (e.g. Phenylketenuria); and perhaps most significantly the percentage of people with a profound handicap with an identified aetiology is steadily increasing. To complement this last development Fryers calls for a new emphasis to be placed on the assessment of disabilities. He suggests that a measure of the extent and nature of the disabilities associated with profound mental handicap form one axis of classification alongside categories of aetiology and neurological impairment.

For this change to take place, we need a comprehensive account of the nature of profound mental handicap and a description of disabilities and behaviour. In particular, special emphasis should be given to communicative behaviours, which are extremely important to caregivers and may represent the bulk of the abilities remaining in people with a profound handicap.

## **2. The Background and Aims of this Research**

Since 1986 I have been working as a research assistant on the 'Moving in Sympathy' project, which is looking at interactions between children with profound handicap and their mothers or carestaff. A major influence on the project has been the new field of movement therapy (Burford, 1986). The role of movement therapists is to establish or maintain communication with people with a profound handicap. The form that this communication takes is strikingly similar to the communication seen between infants and their mothers.

The 'Moving in Sympathy' project has given me the opportunity to study the day to day behaviour of people with a profound handicap at home or in hospitals, in situations where they are alone, with other children with profound handicaps, or with experienced or inexperienced caregivers. This has confirmed the importance of the communicative and emotional abilities of people with a profound handicap, and revealed how little we understand them. It has also shown me how far removed is much of the scientific literature on profound mental handicap from the day-to-day experiences of those that care for them.

This study is intended to address some of these issues. In particular, there are several specific aims of this research:

1.) There is some confusion in the literature over how profound mental handicap should be defined. There is, arguably, no workable, generally accepted definition at present. Tackling this problem is outside of the scope of this thesis, but the problem is recognised in the attempt in the next chapter to carefully describe, using behavioural characteristics, the type of people that are the focus of this study. Generally, the sample used in this research represents a lower ability group within the range of people with a profound handicap. This is a deliberate strategy, as I believe that this group have tended to be neglected by much research conducted in the past.

2.) This thesis attempts a review of the relevant research into people with a profound handicap which has been conducted to date, and a summary of the state of our knowledge.

3.) In this thesis, frameworks which have been used to understand profound mental handicap are reviewed, and an alternative is tentatively proposed, based upon recent developments in mother-infant research.

4.) There is no coherent picture of the nature of the abilities and disabilities associated with profound mental handicap or a baseline for the variations in behaviour. In particular, spontaneous behaviours - especially the communicative behaviours - of people with a profound handicap have only recently come under scrutiny. Wide variations in behaviour and disability are reported among individuals with profound handicap. It was an aim of this thesis to describe a sample of people with a profound handicap: their behaviours, abilities, emotions and handicaps; to examine their awareness, responsiveness and ability to communicate, and catalogue the range of techniques, styles and levels of communicative behaviour used. The variations of these amongst the sample was examined. Two methods of data collection were used: questionnaires completed for each subject by a known carer and detailed video analysis of filmed sessions between subject and carer.

5.) People with a profound handicap are often treated as one group, but there are a great many important differences between individuals. The information from 4.) was used to examine behaviour with respect to several often neglected variables: presence of an additional physical or sensory handicap, residence, and medication. Also, noting

that people with a profound handicap constitute an overwhelmingly heterogeneous group and the benefits for the organization of treatment of identifying subtypes or subgroups, the information was subjected to further statistical analysis in an attempt to identify them.

6.) The implications of the results of this research for the care and understanding of people with a profound handicap will be considered in the final chapter of this thesis. Important issues include assessment (there are few assessment procedures applicable to people with a profound handicap, and these overlook emotional and communicative skills), subgrouping, and the importance of the emotions in the development of all children.

Thus, the following thesis will define the subjects in relation to the classification of profound mental handicap, review research conducted into this group, propose a theoretical framework for planning and interpreting research, and present a study which has collected information on the individual characteristics - particularly the communicative and emotional aspects - of a sample of people with a profound handicap using interviews and direct observation. The implications of this for our understanding of profound mental handicap concludes this thesis.

The first step necessary in conducting this research was to obtain an adequate definition of profound mental handicap. Unexpectedly, this posed several problems. A description of these problems, together with a brief review of the literature on the definition of profound mental handicap, follows in Chapter 2.

## CHAPTER 2. THE DEFINITION OF PROFOUND MENTAL HANDICAP

The first problem facing this research was in defining the subject population. This was something which I really had not anticipated, but even a brief reading of the literature showed that there is serious disagreement amongst authors over both the classification of individuals having profound handicap and the definition of their ability range. The result is that different research papers may identify their subjects as having profound handicap, but they may actually be quite different in ability. In effect, it is possible that the less able of the population of people with profound handicap have tended to be neglected in research.

In this chapter, I will briefly review attempts to produce an adequate definition of profound mental handicap, the problems which such attempts have met, and the consequences of these problems for research. Finally, I will describe the implications of this for this thesis.

### **1. The Classification of Profound Mental Handicap**

Historically, the group presently defined as 'profound' were known as 'idiots', before this word gained its contemporary perjorative meaning. In fact, the two words mean approximately the same. 'Idiot' comes from the Greek word *idiotes*, meaning private person, and 'profound' refers to someone who is 'unfathomable'. In other words, these are people who cannot tell us what they are thinking, whose thoughts are something of a mystery.

With the change in terminology has come a modern attempt at preciseness in the classification. Today, the most widely used classification system for mental handicap is that devised by the American Association on Mental Deficiency (AAMD) (Grossman, 1983) which is based upon a psychometric assessment of intelligence obtained through tests such as the Stanford-Binet Intelligence Scale or the Cattell Infant Intelligence Scale.

The AAMD scale subdivides the population of people with a mental handicap into four groups: Mild, Moderate, Severe, and Profound, defining each of them in terms of their deviation from the scores of the normal population. The average Intelligence Quotient (I.Q.) is 100 with a standard deviation of 15 I.Q. points, and 'Profound', which is the category representing the highest degree of handicap, it defines as possessing an I.Q. below 20 or 25, less than 5 standard deviations below the mean for the population, with a mental age at adulthood less than 3.1 years. Similarly, the other widely used classification system, the World Health Organization (WHO) classification, defines 'profound' as possession of an I.Q. of less than 20.

In principle, then, the classification system is clearly defined, and relies on I.Q. based assessment. In practice, however, there are three major problems.

The first is that researchers may choose to ignore or misuse this classification. Cleland (1979b), points out that although in 1973 the AAMD clearly defined the I.Q. range for Severe Mental Handicap (SMH) as between 20 and 35, in the following years many articles did not conform to these guide-lines, one study which used 'SMH' subjects giving their mean I.Q. as 45! Related to this is the trend not to distinguish between subjects with severe and profound handicap. I will mention more on this later.

A second problem, which contributes to the first, is the difficulty in obtaining an I.Q. for people with a profound handicap. This may appear satisfactory on paper, but in practice their behaviour (e.g. high rates of motor activity, low levels of concentration and attention) and frequently their physical limitations mean that those with a suspected diagnosis of profound mental handicap cannot be tested on standard I.Q. tests. It is also worth noting that even if an I.Q. score could be obtained for someone with an I.Q. below 20, at this level of ability it would surely be meaningless.

A last problem, which follows from the second, is the imprecision of the classification if I.Q. tests are unreliable. Stating that adults with a profound handicap may have an adult mental age (MA) of less than 3.1 years, as the AAMD does, leaves room for a very wide variation in behaviour and ability.

Investigators into profound mental handicap have thus faced problems in defining and describing their subjects. As Shepard and Fagan (1981) point out, some, for example, have used the AAMD definition adding behavioural information, whilst



others have used a combination of chronological age with mental age measured by available tests of infant sensory-motor development such as the Bayley Scales (1969). Norms for adaptive behaviour for all categories of mental handicap are provided by the AAMD for use with the classification, but these have not proved satisfactory.

One option - a thorough listing of the descriptive characteristics of the subjects - would help define the population for other researchers, but this is very rarely taken. Some studies, for example, state that "the subjects were profoundly mentally retarded" and give no further information (Cleland, 1979a). Instead, researchers often present either an estimated I.Q. or occasionally a score representing adaptive behaviour or general development, obtained through a wide variety of assessments.

Hogg et al (Hogg, Foxen and McBrien, 1981) note the inadequacy of I.Q. criteria and suggest a definition which, while not using intellectual assessments, is still based on normative assessment (comparison with figures for the normal population). This definition is derived from developmental scales, the term 'Profound Retardation' being applied to children whose mental age is less than or equal to one quarter of their chronological age. This is an interesting development, but the low reliability in testing people with a profound handicap remains a problem.

One trend is to define people with a profound handicap in terms of the services received by them. Often, this will refer to educational services. In the United States, for example, before changes in the law in the 1970's people with severe handicap were (and often still are) referred to as the 'trainable mentally retarded', people with a profound handicap as 'untrainable'. Similarly, prior to 1975 in Scotland profound retardation was defined in terms of its exclusion from educational services, people with a profound handicap being considered ineducable. The danger in this, of course, is that the classification may not be an active process and that if this classification is not regularly reviewed a mislabeling may have severe long term effects.

An alternative approach, and one that is more directly applicable to practice, is to define profound mental handicap in terms of a description of the functional skills that are possessed or absent. Presland (1982) defines children with profound handicap or 'Special Care' children with a list of characteristics: there is a virtual absence of ability to speak or understand any language; many are not or are barely ambulant and often suffer from some form of Cerebral Palsy (C.P.); most have great difficulty manipulating objects in the environment; there is usually an inability to feed, dress or

attend to toilet needs; Many have had convulsions; some have serious sensory deficits; some are on forms of medication which reduce alertness and may even make them sleepy most of the time. He also emphasizes the fact that they need continuous nursing care.

Sontag, Burke and York (1973) also use a list of characteristics to describe children with profound handicap, stating that they are usually not toilet trained, display severe behaviour problems, are nonverbal, delayed in self-help, social and motor skill development and may suffer from severe physical or sensory impairments. A similar list of characteristics has been given by staff interviewed in a survey of children with profound handicap in Scotland (Browning, Bailey and Clark 1981).

A recent attempt at a comprehensive definition has been made by the National Development Team (1985), an independent, government funded body advising mental handicap services in Britain. Classification is made according to degree of dependency, the criteria for the lowest level (group IV) being "severe double incontinence, multiple physical handicaps, severe epilepsy, extreme hyperkinetic behaviour, and aggression to self and others" (p.43). It adds that the majority of this group require some form of long-term residential care, with a higher staff ratio than is required by the other groups.

This trend is promising, but definitions involving negative defining attributes rather than an assessment of capabilities has received considerable adverse criticism since such an approach ensures that no attempt is made to characterise what is achievable within a given ability range. Also, they tend to be imprecise in detailing which of the characteristics are found in all individuals with profound handicap, and which are found in some. It may appear that the list of diverse characteristics listed all have to be present before a classification of profound mental handicap may be made, when in fact it is unlikely that they will all be found in any one individual. Similarly, the emphasis these definitions give to physical handicap mean that they neglect those people with profound handicap who do not suffer from any additional physical or sensory handicaps but nevertheless suffer from a similar intellectual impairment.

There are problems, then, in developing appropriate classificatory criteria for profound mental handicap. What consequences does this have?

## **2.2 Do We Need a Definition of Profound Mental Handicap?**

No one doubts the importance of a workable definition. As the AAMD manual states: "any attempt to plan broadly based programs for this highly heterogeneous population or to shed light on the frequency and distribution of certain diagnostic conditions and their possible causes requires a well-defined system of classification" (Grossman, 1983, p. viii). Unfortunately, there is no well-defined system of classification for people with a profound handicap.

This situation has important consequences for research. First, people with profound handicap may be included in studies as part of the population of people with severe handicap, and differences between these two groups not referred to. Second, the wide definition of profound mental handicap may result in a biased selection of subjects with profound handicap.

Perhaps the most common of these is the tendency among researchers to treat the severely and profoundly handicapped as one group, and to use the two terms interchangeably. Cleland and Rago (1978) argue that many assume that "at such low functioning levels, exact terminology makes little difference". Typically, an article will use as the descriptor 'the severely and profoundly mentally retarded'. Often, however, the study will include only subjects with severe handicap, or if it does include subjects with profound handicap the results are given for the group as a whole and no separate results for these subjects are presented, which limits the usefulness of the study. If a study uses a mixed SMH/PMH population and some subjects fail a task or are removed from the study because of behaviour problems or untestability, the correct identification of these subjects as having profound handicap is obviously very important. Another major criticism is that many of these studies do not give enough information on their subjects - particularly descriptive characteristics - to allow a correct identification of the severity of handicap and future replication.

The extent of this problem can be seen by looking at the literature on people with a profound handicap, and noting how often people with severe handicap are also mentioned as subjects, and in the title. Table 2.1 (over) presents this information for all 670 articles which referred to people with a profound handicap published from 1974-1988.



Table 2.1 PMH and SMH in Journal Articles: 1974-1988

	S U B J E C T S :			T I T L E S   O F   P A P E R S :		
	TOTAL	PMH & SMH	PMH ONLY	PMH & SMH	SMH ONLY	PMH ONLY
74-82	346	156 (45%)	190 (55%)	76 (22%)	18 (5%)	119 (34%)
82-88	324	179 (55%)	145 (40%)	51 (16%)	44 (13%)	71 (22%)
Total:	670	335 (50%)	335 (50%)	127 (19%)	62 (9%)	190 (28%)

As can be seen, half of the articles which feature subjects with profound handicap also feature subjects with severe handicap. Of these, only three papers draw distinctions between them, in the rest they are treated as the same population.

Similarly, an idea of how researchers view people with a profound handicap can be obtained by examining the titles of papers. Only 28% specifically mention profound handicap without severe handicap; 19% refer to both; and 9% refer only to the severe handicap, although these papers later stated that they had also used subjects with profound handicap. Clearly, some authors seem to be treating these two populations as the same. How many studies actually do use subjects with profound handicap remains open to question, but without adequate information on characteristics this is hard to answer.

These criticisms are far from new. Cleland and Rago (1978) and Cleland (1979a,b) have called the 'lumping together' of people with severe and profound handicap "indefensible". They give several reasons: the more refined the subgroup, the more likely it is to yield useful knowledge, and the more likely it is to be replicated. In addition, there is a danger that parents of people with a profound handicap may be misled by successful results obtained with people with severe handicap, and unrealistic expectations may be raised. Initially, this may be what the carer wants to hear, but the end results may be distressing and unnecessary. Similarly, Westling (1985) has made a plea that the importance of educational programs specific to people with a profound handicap be recognized, and that their teachers receive appropriate training. Tomkiewicz (1974) has argued that a precise definition and classification is of primary importance to epidemiological and medical studies of mental handicap, and Kushlik and Cox (1973) have found that crude behavioural data were superior to even detailed clinical descriptions for planning and evaluating services.

Perhaps the strongest attack on the mislabeling of people with a profound handicap in research is by Switzky et al (Switzky, Haywood and Rotatori, 1982) in which they lamented that little had changed following Cleland's condemnation of the grouping together of subjects with severe and profound handicap. Unfortunately, as can be seen from table 2.1, this is still a real problem. This problem is not restricted to research. Although there is basic agreement on the characteristics of people with a profound handicap amongst carers, until this is clearly stated there will be large differences in classification between different institutions, different services and different geographical areas. In a survey of 20,000 institutional residents of different institutions in the U.S., Cleland, Case and Manaster (1980) showed that rates of classification of profound mental handicap and attributed aetiology varied greatly.

These problems are not easily dealt with. If psychometric, developmental or behavioural criteria are used in defining degree of handicap then there is an assumption of continuity. There is thus no clear boundary between people with severe and profound handicap, but a continuum of ability. To some extent, then, the chosen boundary between profound and severe handicap is arbitrary. Nevertheless, this does not detract from the importance of recognising that there are overall differences in ability between the two groups.

There are similar problems in research which is restricted to subjects with profound handicap. Profound mental handicap can be thought of as a continuum, within which, as indicated above, there are very wide variations in ability and a blurred boundary with severe mental handicap. It is worth attempting to briefly outline the characteristics of profound mental handicap and the amount of variation within this classification.

Generally, there is a high incidence of physical and sensory handicaps in people with profound mental handicap (O'Connor, Justice, and Payne, 1970), although not all have such an additional handicap. Many people with profound handicap have no intelligible speech at adulthood, though some do develop limited speech. Similarly, they typically experience varying levels of difficulty in learning an alternative communication system. In addition, they have poor or absent socialization skills. As

MacAndrew and Edgerton noted back in 1964

"they create symbols only rarely if at all, they sustain little culture, develop few rules of their own, evidence relatively little exploratory curiosity, and their interaction with one another is both minimal and peculiarly 'ahistorical'." (MacAndrew and Edgerton, 1964, p.318)

Overall, people with a profound handicap have an extremely impaired ability to learn, with particular problems in generalization. Self help skills such as feeding, washing, dressing, or attending to toilet needs are usually poor or absent. As a group, they have a high incidence of delayed puberty, epilepsy, pica (ingestion of found objects), self-injury, stereotypy, mutism, echopraxia (automatic and meaningless repetition of sounds), rumination (regurgitation of food), and abnormal EEG's (Cleland and Swartz, 1982), though again many individuals do not show these characteristics .

Within the classification of profound mental handicap, then, there is a wide range of ability. There is thus a possibility that studies investigating profound mental handicap may use as subjects people who have been correctly identified as having profound handicap, but who represent the higher ability ranges of this group. Is this a valid concern?

Cleland (1979a) is amongst those who have pointed to a tendency amongst researchers to use subjects who will perform well enough to produce results. There is a tendency, because of restrictions in time and budget, to use subjects who will create less problems. Cleland calls this the 'HOUNDS-YAVIS' phenomenon: Homely, Old, Ugly, Non-verbal, and Dumb subjects are neglected, and Young, Attractive, Verbal, Intelligent, and Successful subjects are used. This results in research into profound mental handicap which has little relevance for those people who fall into the less able part of this population.

Thus, to select a limited number of examples, Whittaker (1980) examines the performance of 34 children with profound handicap on Lowe and Costello's Symbolic Play Test. These children, described as having "either no speech or the ability to use no more than 15 single words" (which is rather imprecise), were able to use a toy knife and fork appropriately. Many people with profound handicap do not have this ability. Similarly, accounts of verbal training of people with profound handicap by Barton (1973), Richmond and Lewallen (1983), and McCuller and Salzberg (1984)

appear to have used quite able subjects. In Barton's study, for example, all subjects demonstrated the ability to use appropriate speech or signs at the beginning of the studies, sometimes being capable of verbal statements or even participating in very simple conversation (Barton, 1973). Again, many other people with profound handicap do not possess this ability.

In summary, there are problems in reaching a definition of profound mental handicap which has led to problems in research. Some studies have treated people with profound and severe handicap as a single population, whilst other studies may have neglected less able people with profound handicap.

### **3. Classification of the Subjects Used in this Research**

Tackling the problems of the classification of profound mental handicap was outside the scope of this research. The problems outlined above left me with several concerns, however. During the 'moving in sympathy' research, I had been involved with subjects who represent the lower ability ranges of profound mental handicap and had become aware of the relative lack of knowledge concerning this group. In view of the reservations expressed above concerning the relatively high level of ability of subjects in much research into profound mental handicap, and the tendency not to distinguish between groups of people with severe and profound handicap, I felt strongly that this research should not be open to such criticism. In addition, I was aware that in investigating the communicative and emotional abilities of people with a profound handicap, it was important to determine whether the presence of such abilities could be discerned in people who are functioning at the lowest levels of profound mental handicap.

In selecting subjects for this research, then, I determined to ensure that they represented the lower ability ranges of profound mental handicap. In practice, all subjects had been classified by the services with which they were in contact as having a profound handicap. I did not carry out any further testing, but used observations and discussions with carers to confirm the level of functioning with respect to the classification systems of the AAMD, Presland (1982) and the National Development Team (1985). I then used a further set of criteria as part of the research strategy designed to exclude more able subjects. This is given in Table 2.2 (over).

<b>Group A</b>	<i>Failure of mental development</i>
1. <b>No formal/symbolic expressive or receptive communication</b> , including speech or sign systems. If some words or signs are known, vocabulary must be less than five and they must not be used in combination. Fantasy play is absent.	
2. <b>Extreme learning difficulty</b>	
<b>Group B</b>	<i>Absence of basic self-help skills</i>
3. <b>Inability to feed self.</b>	
4. <b>Inability to dress self.</b>	
5. <b>Inability to wash self.</b>	
6. <b>Double incontinence.</b>	
<b>Group C</b>	<i>Abnormalities of motor initiation and coordination</i>
7. <b>Abnormal Motor control</b> , ranging from severe (non-ambulant) to mild (abnormal posture or ungraceful movements). Defective fine motor control and manipulatory skills.	
8. <b>Stereotyped and/or bizarre movements</b> including self-injurious behaviour .	
9. <b>Abnormal vocalizations</b> ; Usually repetitive, non-speech. Includes screaming and inappropriate or meaningless use of speech (i.e. words used in inappropriate context).	
<b>Group D</b>	<i>Additional handicaps or disorders</i>
10. <b>Physical handicap or sensory handicap or combination.</b>	
11. <b>Epilepsy</b>	
12. <b>Additional illnesses</b>	

Table 2.2 Criteria for Subject Selection

The most important aspect of these criteria is the emphasis on formal or symbolic language development, described in group A of the table. This was used to distinguish between those people with profound handicap of higher and lower ability. This criterion was selected because of the emphasis upon communication in the research, and because it is representative of general mental development. To ensure that those people with profound handicap who do not possess a language system but are able to distinguish between a limited number of words are not excluded, further



criteria were added including possession of a vocabulary of less than five words or signs, which are not used in combination.

The other criteria restate aspects of the classification systems described above. They were not used as criteria in their own right, but as a complimentary guide in order to confirm that the absence of language was representative of a low level of ability. The other criteria in Group A, and the criteria in Group B, are characteristics of people with severe and profound handicaps to a varying degree, less able people with profound handicap having a more extreme learning difficulty, and poorer self-help skills. The criteria in Groups C and D were not necessary for inclusion, but an awareness of them was helpful. They represent characteristics which may be present in people with all degrees of handicap. The probability of their presence increases with degree of handicap, however.

In this chapter some of the problems in the classification of profound mental handicap, and the implications of this for research, have been described. A new definition is beyond the scope of this thesis, but an awareness of these problems has been important in the design of the research and has led to the development of additional criteria to ensure the exclusion of more able subjects.

In the next chapter I will discuss in more detail what research has told us about people with a profound handicap, and what research still needs to be done.

## CHAPTER 3. A REVIEW OF RESEARCH ON PROFOUND MENTAL HANDICAP

Mental handicap is one of the largest but the least researched of all areas of psychiatry, psychology and social work, and profound mental handicap is the least researched area of mental handicap. This statement has perhaps become something of a cliché, but many parents and professionals feel that it is still true. In this chapter, I will attempt to review a substantial amount of recent research conducted with people with profound handicap.

To do justice to this topic I have chosen to include research on all aspects of profound mental handicap, believing that many aspects are inter-related and that findings from one area may have benefit for another. I also believe that since this thesis is examining fundamental characteristics of profound mental handicap, it is important to take note of how other researchers and groups of researchers have seen them.

This review will attempt to give an overall picture of what the many strands of research on people with profound handicap have told us about them, and on which aspects they have had nothing or very little to say. Generally, it suggests that although our knowledge of people with profound handicap has increased significantly in the last twenty years or so, there is still much that we do not know. It also shows that the number of studies involving people with profound handicap is still lamentably small when compared to the effort put into research on other forms of disability.

### **1. Research with people with profound handicap: The Sources**

There are two textbooks on people with profound handicap, one published in the U.S. (Cleland, 1979a), and one in Britain (Hogg and Sebba, 1986). Both contain excellent summaries of some areas of research, although their emphasis is quite different and the second book does not mention the first at all. Hogg and Sebba concentrate on those who have additional sensory and physical handicaps and write extensively on problems of education, training and assessment. Cleland, in contrast, offers a review of the characteristics of those people with profound handicap who are

living in institutions, taking an ethological approach to their behaviour and capabilities. Both approaches are valid and useful.

There are now several good textbooks on mental handicap in general, written from a wide variety of approaches, including a multi-disciplinary approach (Craft, Bicknell and Hollins, 1985) and a nursing approach (Shanley, 1986). The quality of the content relating to people with profound handicap varies a great deal, however, and the vast majority of general textbooks do not cover their special requirements of care. Similarly, conference reports, while covering research into all levels of mental handicap, contain few studies relevant to people with profound handicap, among which, however, some are excellent.

In the journals, the last two decades have seen a great increase in the number of studies purporting to deal with people with profound handicap and many exciting and challenging findings have been reported. When looked at in relation to psychology as a whole, however, the number of studies that are strictly relevant to people with profound handicap is small, and distinct and narrow trends can be seen in the type of studies reported.

I have identified in Psychological Abstracts all of the papers published over the last 15 years that included a reference to profound mental handicap. The total number of papers published was 670. This figure includes those studies or reviews which also feature subjects with other degrees of handicap. Psychological Abstracts covers 1400 journals in 29 languages, from 54 countries. Papers on profound mental handicap have been published in 11 of them: Britain, the U.S., Japan, Germany, France, Norway, the U.S.S.R., Ireland, Canada, Australia and New Zealand. It can be seen, then, that the figure of 670 papers in 15 years is far from impressive in relative terms, although it should also be stressed that there are other important sources, for example in the education literature.

I have prepared a breakdown by topic for all of these papers (Table 3.1), dividing them into two periods: those published between 1974 and 1982, and those published between 1983 and 1988.



**Table 3.1 Topics of Journal Articles Relating to PMH: 1974-1988**

	1974-1982(%)	1983-1988(%)	Total(%)
Classification	3(0.9)	4(.2)	7(1.0)
Epidemiology	2(0.6)	8(2.5)	10(1.5)
Aetiology/Biology	3(0.9)	12(3.7)	15(2.2)
Assessment	21(6.1)	14(4.3)	35(5.2)
General/Research Issues/Misc.	8(2.3)	13(4.0)	21(3.1)
Provision of Services: General Issues/Planning	5(4.3)	9(2.8)	24(3.6)
Provision of Services: Education	31(9.0)	1(3.4)	42(6.3)
Provision of Services: Vocational Planning	5(1.4)	4(1.2)	9(1.3)
Provision of Services: Residence/Institutions	5(1.4)	10(3.1)	15(2.2)
Aspects of Care: General Issues	6(1.7)	9(2.8)	15(2.2)
Aspects of Care: Staff/Organization	4(1.2)	10(3.1)	14(2.1)
Aspects of Care: Therapies	2(0.6)	8(2.5)	10(1.5)
Aspects of Care: Leisure	7(2.0)	6(1.8)	13(1.9)
Aspects of Care: Pharmacology	4(1.2)	13(4.0)	17(2.5)
Cognition	4(1.2)	4(1.2)	8(1.2)
Behaviour Modification/Training	139(40.2)	136(42.0)	275(41.0)
Behaviour: General Aspects	18(5.2)	5(1.5)	23(3.4)
Behaviour: Behaviour Problems	12(3.5)	23(7.1)	35(5.2)
Communication Training	28(8.1)	12(3.7)	40(6.0)
Interaction: Mother-Infant Interaction	1(0.3)	1(0.3)	2(0.3)
Interaction: Interaction Studies	4(1.2)	3(0.9)	7(1.0)
Interaction: Attempts to improve Interaction	11(3.2)	5(1.5)	16(2.4)
Development	13(3.8)	4(1.2)	17(2.5)
Totals:	346	324	670

This is not a definitive list, but is intended to give an impression of the most popular areas of research. The division into two periods also enables a suggestion of trends in research. A more detailed summary of these articles is given in Appendix I.

From the table it can clearly be seen that behaviour modification is by far the most consistently popular subject for journal articles. Combined with communication training studies, which use behaviour modification techniques almost exclusively, it amounts to almost 50% of the total.

In contrast, studies of classification are extremely few, and only two of these question the application of present definitions. Although studies of epidemiology and aetiology are also few in number, there does seem to have been an increase in the last five years, perhaps reflecting new developments in medical techniques or an interest in medical topics, which may also be reflected in the increase in the number of studies on pharmacology.

Another increase in recent years is in the number of studies on the effects of residence and the changes which follow a move from an institution into the community, which is now an important and controversial issue in mental handicap. These studies (a total of 15) are still very few in number, however. In contrast, articles on education were numerous in psychological literature during the 1970's, when laws regarding the rights to education were undergoing change.

The number of papers on general aspects of the behaviour of people with profound handicap, which range from a few ethological studies of group behaviour to studies of handedness distribution, is notably low, though there has been an increase in studies of behaviour problems. This last figure only includes reviews and attempts to isolate important contributing factors - papers reporting treatments using behavioural techniques being counted as behaviour modification studies - and should therefore be recognized as an underestimate of the total interest shown.

Studies of interaction between individuals with profound handicap and other persons, it should also be noted, are extremely rare. Although some studies into the effects of residence included a measure of interaction as part of the design, only 7 studies concentrated on interaction alone, and only two studies looked at infants with profound handicap and their mothers. There were, however, a number of studies which attempted to improve the rate of interaction. The majority of these, again, used a behaviour modification design.

This summary makes clear that, while, overall, the number of studies on people with profound handicap is small, trends in the research have meant that some potentially important areas have received almost no interest at all. In particular, the table shows the dominance of behaviour modification studies and a general lack of interest in aspects of behaviour such as communicative interaction unless it is part of a behaviour modification paradigm. In the rest of this chapter, I shall review research from all of the areas mentioned in the table, but will pay particular attention to what we have learnt from studies of the behaviour of people with profound handicap, a neglected but potentially extremely important source of information.

## **2. A Review of the Findings of Research into Profound Mental Handicap**

### *2.1 The Epidemiology of Profound Mental Handicap*

Estimates of the prevalence of profound mental handicap vary with the type of definition chosen, the age range looked at, and the method of ascertainment. Some studies do not count still births while others do. Some studies include referrals only, and therefore represent a gross underestimate. There is also a further complication arising from the confusion between severe and profound handicap in the prevalence data.

McLaren and Bryson (1987) report that most studies agree on a figure between 3-4 in 1000 for the prevalence of severe mental handicap, and that estimates for the profound has ranged from 3.4/1000 to 0.5/1000. They suggest 0.4 in 1000 represents a reasonable value for the prevalence of profound mental handicap, and argue that this figure is probably more reliable than the figure for severe handicap because, given the additional severity of profound handicap, there is less room for error. This conclusion may be too optimistic. Fryers (1984), points out that surveys of people with profound handicap are "seldom the product of high-quality data" (p.157), and that studies are characterized by poor testing. In a long term study of 5-9 and 10-14 year olds conducted by Fryers in Salford, the ratio for the prevalence of profound handicap was found to remain stable at 1.0/1000 for almost 20 years, although the ratio for severe handicap varied considerably. More recent data from this study suggest that the ratio for profound handicap may be reducing slightly, the ratio for 5-9 year olds between 1976 and 1980 falling to 0.7/1000.

Fryers believes that differences in operational criteria make comparisons with the relatively few relevant studies redundant, but those looking at similar ages have suggested roughly similar prevalence ratios. MacKay (1971), for example, in a study based in Northern Ireland, found ratios of 0.56 (ages 5-9) and 0.64 (ages 10-14), and in a follow up study (McDonald and MacKay, 1978), 0.54 and 0.65. Therefore a figure of slightly less than 1/1000 for school age children seems a reasonable estimate.

One interesting aspect of Fryers' data is that the proportion of people with profound handicap in the total population of people with severe handicap fell progressively from 50% of the total in 1961 to 20% in 1980. Assuming methodological problems are not to blame, there are several possible explanations for

this. One major factor, seen in several studies, is a greater susceptibility to illness in people with profound handicap, and a greater instance of other medical, physical and sensory complications. Cleland (1979a) reported that the most common cause of death was pneumonia (36.5%), followed by myocarditis (8.9%), cardiac failure (8.9%) and tuberculosis (8.4%). It is likely that medical advances that have increased longevity in the general handicapped population have had less of an effect on people with profound handicap. Certainly, the life expectancy of people with profound handicap remains low: Cleland and Patton (1965) put it at only 38, whilst McLaren and Bryson (1987) found that only 68% live to age 20 (though many may live considerably longer).

Other factors that may be contributing to the decline in the proportion of people with profound handicap in Fryers' data are a general reduction in the severity of handicap in children with a mental handicap born more recently as a result of medical advances, and an increase in the optimism of assessments. It is difficult to test these explanations, but it is probable that all play a part.

## *2.2 The Aetiology of Profound Mental Handicap*

Well over 200 causes of mental retardation have been identified. No other group has as varied an aetiological representation as people with profound handicap. The intellectual and frequent physical and/or sensory handicaps in profound mental handicap may result from physical trauma, infection, chromosome or metabolic disorder or from a variety of obscure perinatal disorders. Table 3.2 (over) shows the prevalence of different causes in severe and profound handicap.

Some of these causes will typically not result in profound mental handicap (e.g. Down's Syndrome), but can do so if they are in combination with other causes. In fact, profound mental handicap may often be the result of more than one causal factor. In addition, the same cause can often have different outcomes - the long term effects of infections, for example, are determined by age and severity of infection. The growing brain is particularly susceptible to damage in certain areas at certain times.

DISORDER	EFFECT	FREQ.
<b>PRENATAL:</b>		
1 Genetic:		
.1 Chromosomal errors:		
.11 Down's Syndrome		
a. Trisomy 21 (94%)	M-SMH	0.6-56
b. Trisomy mosaics (3%)	var	0.03
c. Translocation (3%)	M-SMH	0.03
.12 Other Autosomal anomalies ( <i>cri du chat syndrome</i> )	var/M-SMH	2
.13 Sex chromosome disorders ( <i>Klinefelters syndrome</i> )	var/M-SMH	3
.14 Nonspecific disorders		
a. Recessive	M-SMH	0.5
b. X-linked	M-SMH	0.1-1
.15 Unclear mechanism ( <i>Severe hypercalcaemia</i> )	M-SMH	?
.2 Inborn biochemical errors:		
.21 Defects of protein metabolism ( <i>Phenylketenuria</i> )	SMH-curable	.05-0.2
.22 Defects of carbohydrate metabolism ( <i>Galactosaemia</i> )	SMH	0.02
.23 Defects of lipid metabolism ( <i>Tay Sachs, Battens disease</i> )	M-SMH	0.04?
.24 Defects of mucopolysaccharide metabolism ( <i>Hurlers synd.</i> )	SMH	0.03
.25 Defects of hormone system ( <i>Congenital Hyperthyroidism</i> )	SMH-curable	0.1-1.6
.26 Unclear mechanism ( <i>Epilepsia, Microcephaly</i> )	var	0.01?
2 Communicable disease:		
.1 Rubella	var/SMH	.03-0.1
.2 Cytomegalovirus	MMH (rare)	2-23
.3 Toxoplasmosis	MMH (rare)	0.2-1
.4 Syphilis	very rare	v. rare
3 Neural tube defects ( <i>Spina Bifida, Hydrocephalus</i> )	10% SMH	1-8
4 Rhesus incompatibility	var/MMH	rare?
5 Other toxic agents ( <i>Alcohol/chemical fetopathy</i> )	var/SMH	var
<b>PERINATAL:</b>		
1 Gross trauma/cerebral thrombosis/hypoxia	var	?
2 Cerebral palsy ( <i>various aetiology</i> )	25% SMH	2-24?
<b>POSTNATAL:</b>		
1 Physical trauma	var	var
2 Communicable disease:		
.1 Encephalitis ( <i>TB</i> )	var	var
.2 Encephalopathy ( <i>pertussis, measles, mumps</i> )	var	var
3 Toxic agents	?	var
4 Lack of nutrition	var	?

**Table 3.2 The Aetiology and Estimated Frequency of SMH and PMH**

Prevalence rate (frequency) is the number per 1000 in the general population.

Examples of conditions are given in brackets.

KEY:

MMH= mild mental handicap

SMH= severe/profound mental handicap

var = variable

? = unknown.



The large number of possible causes and the uncertainties in outcome results in a very confusing picture. Even with the medical advances of recent years it is estimated that around 40-50% of cases of profound mental handicap still have an 'unknown' aetiology (Clarke, Clarke and Berg, 1986). Nevertheless, many investigators (e.g. Hagberg and Hagberg, 1986) believe that with more investigation the precise causes of most cases of profound mental handicap can be identified. This conclusion is supported by the few studies reporting large scale chromosome analysis of the people with a mental handicap. Carrel, Sparkes, and Wright (1973), looking at 121 patients with mild to profound handicap with no diagnosis, found 19 (15.7%) had a significant chromosome abnormality. Warter et al (Warter, Bon, Ebtinger and Clavert, 1977) found similar numbers, but point out that in many cases the handicap arises from a multi-faceted aetiology, with other environmental factors aggravating a problem originally of purely organic origin.

Similar progress has been made using different techniques of investigation. Reid et al (Reid, Martin, Ballinger and Heather, 1980) found higher levels of antibodies to the Herpes Simplex virus in a group of subjects with severe and profound handicap with an 'unknown' diagnosis, implicating Herpes infection as a possible cause of handicap, and Hollis, Draper and Samson (1983) have found an inverse relationship between level of handicap and amount of serum immunoglobulin-G in 13 children with profound handicap.

In practice, however, an 'unknown' diagnosis is still commonly used. Moreover, there are many variations in how criteria for diagnosis are applied. Cleland, Case and Manaster (1980) found large differences in aetiological assignments between different institutions. At one large institution, for example, they found 60.63% of people with profound handicap diagnosed as 'unknown', at another, only 6%. Similarly, a general diagnosis of an 'organic' cause varied from 22.9% to 99.03%.

Most diagnoses of people with profound handicap are inferred, usually from the case history. Incredibly, up to 50% of diagnoses list several possible alternative causes (McLaren and Bryson, 1987). Frequently, where one cause is cited, this may be no more than a contributing factor, or even itself the result of the handicap. A difficult birth, for example, may be the cause of the mental handicap or it may be a consequence of a genetic fault or abnormal development in the womb which is the real cause of the mental handicap.

### *2.3 Additional Handicaps in people with profound handicap*

Multiple impairment - the presence of mental retardation combined with additional physical or sensory impairment - is common in people with profound handicap. Generally, the chances of additional handicaps being present increases with the severity of mental handicap (McLaren and Bryson, 1986). There are three possible reasons for this: that the mental handicap and sensory handicap share a common cause (e.g. visual defects in rubella, or Cerebral Palsy caused by difficult birth); that they are part of the same disordered process of development (e.g. Spina Bifida); or that they represent an apparent coincidence (e.g. thyroid deficiency in Down's Syndrome) (Fryers, 1984).

The precise frequency of additional physical handicap is hard to determine exactly, and most investigators conclude that more research is needed. Fryers (1984) found that most of the people with profound handicap in the Salford study had epilepsy, cerebral palsy, or both. Browning, Bailey and Clarke (1981) estimate that 35% of people with profound handicap have severe physical impairment, rising to 46% in those hospitalized. The National Development Team report (1985), which looked at 5,530 hospital residents with profound handicap, found 16.4% could not walk without help.

As a group, people with profound handicap typically show poor coordination of motor skills and have difficulty in fine control when manipulating objects. If they are ambulant, the skills involved are commonly less accomplished than in the normal population resulting in unusual movement characteristics and a clumsy appearance. There are, however, wide individual differences, with some individuals showing all the intellectual deficits of profound mental handicap but having good fine control of manipulation and fast, accurate, movements.

The effects of abnormal motor development on other aspects of development are important. The inability to maintain or change posture and orientation in space is likely to have consequences for the development of communication and in perceptual and cognitive developments that rely on an active and controlled transformation of experience of the world of objects. The extent of these effects on development are largely unknown in people with profound handicap.

Epilepsy is the most common disorder associated with mental handicap and occurs in 15-30% of this population (McLaren and Bryson, 1987). This figure increases dramatically with the severity of handicap, though a note of caution is given in two recent studies (Neill and Alvarez, 1986; Holmes, McKeever and Russman, 1983) in which EEG recordings were used to show that in many cases behaviour which is classified as epileptic actually has no epileptic basis.

Sensory impairment, also, is not uncommon in people with profound handicap, and Hutton, Talkington and Altman (1973) have noted that with increasing levels of retardation there is increasing incidence of sensory impairment. Estimates of frequency are difficult, however. For many people with profound handicap testing for sensory impairment may prove impossible, and staff reports are usually relied upon rather than formal testing. Though some assessment procedures have been developed - Rogow (1978), for example, has devised a test for use with the blind, and Silva, Friedlander and Knight (1978) with the deaf - they are still not widely used. In addition, it is possible for deficiencies in sensation to improve or deteriorate over time.

For the above reasons, figures are generally assumed to underestimate prevalence of sensory deficiency in people with profound handicap. Although studies tend to use different definitions, representative figures for prevalence and degree of sensory impairment come from Browning et al (Browning, Bailey and Clark, 1981) who report that 3% of people with profound handicap are deaf, 5% have partial hearing, 9% are blind and 12% are partially sighted. The National Development Team found lower rates: 5.2% were blind and 3.8% were deaf. In contrast, Sadowsky (1985) used more flexible definitions and found, looking at one region in California, that 46.4% of people with profound handicap had some form of visual impairment. He also found that impairment increased significantly with severity of handicap, a finding echoed by Zoller, Ruhe and Dunster (1985) in their tympanometric screening for auditory impairment. It should also be noted that there are a number of cases of visual and auditory impairment occurring in the same individual in people with profound handicap - Sadowsky found this to be as high as 22% - and it is not uncommon to find an individual with profound handicap who is both completely blind and profoundly deaf.

As with motor dysfunction, sensory impairment undoubtedly plays a major part in the disruption of normal development, and this may not be fully appreciated when the sufferer also has a profound handicap.



Although rarely the direct focus of attention, there is evidence that the nervous system of people with profound handicap often has diffuse, abnormal characteristics. In particular, the pain thresholds of many of people with profound handicap may be unusually high. There are many anecdotes of individuals with severe or profound handicap being burnt by standing too close to a radiator and showing no distress, or feeling no pain at the dentist (Cleland, 1979a). This may be related to extent of brain damage, and is not seen in all people with profound handicap. In contrast, the senses of touch, taste and smell are often neglected, but in individuals with handicaps in the major senses of sight and hearing, stimulating these other senses can be an effective form of therapy.

A finding common to all studies of the prevalence of mental handicap is that the chances of an additional impairment being present, and the severity of this impairment, both increase dramatically with the degree of mental handicap. People with profound handicap are therefore the most likely to suffer from a range of devastating physical and sensory deficits, in addition to their intellectual impairments.

#### *2.4 Extent of Brain Dysfunction*

The frequent uncertainty about the cause of profound mental handicap in individuals is reflected in the lack of knowledge about the extent and location of damage to the brain in this condition. It is difficult to represent any discrete structure-function relationship where defects in behaviour are so devastating and cortical pathology is presumed to be so extensive. Most investigators have viewed profound mental handicap as a result of near total neocortical dysfunction, with people with profound handicap showing no signs of higher mental functioning.

As a general rule, pathologies of brain growth do not destroy single brain structures but rather extensively alter the brain architecture produced by subsequent growth (Dobbing and Balazs, 1984). Damage can be understood as consequences of direct destruction or deformation of connections, or of anomalies of neuronal migration or cell death. Crucial factors determining the extent of damage are the inflicting agent and the stage of brain development, particular brain areas undergoing growth at different, highly vulnerable, times. Unfortunately, the brain's capacity for plastic recovery from damage appears limited in man, and early brain damage may result in widespread anatomical abnormalities.

The development of most individuals with profound handicap seems to be abnormal during ante- or peri-natal stages. This may depend upon the cause, however, some metabolic disorders not affecting development until many months after birth. In these cases it is difficult to ascertain how normal development had been before problems were first noticed. In Rett's Syndrome, for example, the period of apparently normal development before regression begins at around 9 months is now thought to hide subtle signs of abnormality (Kerr, Montague and Stephenson, 1987). The great individual variations in the condition of people with profound handicap must always be borne in mind.

On gross neuropathological examination, 15% of the brains of people with a mental handicap show no signs of abnormal growth (Penrose, 1972). The majority, however, show differences in fine structure, including terminal axon, synapse and dendrite formations. Axonal and dendritic growth is particularly vulnerable in the developing brain, but accurate evidence regarding the effects of various perinatal disorders on dendritic and synaptic development is practically non-existent. Studies which have examined the brains of people with profound handicap are extremely rare.

Huttenlocher (1975) has examined the brains of six children with profound handicap (two had a genetic disorder, four were of unknown aetiology) and found marked defects in the number, length and spatial arrangement of dendrites and synapses. He proposes that a number of different aetiological factors can result in general stunted development of brain structures if they act during the period of rapid synaptic and dendritic growth, from the last trimester of pregnancy to the end of the first post-natal year. Evidence from the examination of adult brains, however, has shown no consistent dendritic abnormalities. Huttenlocher suggests this may result from differences in technique or evidence of 'catch up growth' (though apparently with no corresponding behavioural improvement). Clearly, we need more information.

Cowrie and Cole (1986) argue that neuropathological examination of postmortem brain tissue, which is presently very infrequent, could provide valuable information on aetiology and diagnosis. This would be useful in counselling relatives, and may help in the diagnosis of individuals with similar handicaps. At present, most of the information on the brains of people with profound handicap is anecdotal and based on extremely gross observations made during brain surgery.

It is impossible to deduce details of brain damage from observing behaviour, but whatever the precise nature of the structural damage, the functional outcome in profound mental handicap appears to be a dysfunction of much of the cerebral cortex. The inability to acquire any formal language production and comprehension skills and the severe difficulty shown in simple learning tasks are consistent with this view, as is the high incidence of visual and auditory disorders. It is worth noting, however, that some people with profound handicap whilst showing all other intellectual indications of profound mental handicap, do not show any obvious problems with motor control, raising questions about the extent of damage to the posterior frontal lobes (motor cortex). More often, though, there are serious motor problems, and these may represent damage to some cortical sites, with some motor problems indicating additional brain stem (e.g. basal ganglia) and cerebellar dysfunction.

Many subcortical areas of the brains of people with profound handicap do appear to be functioning at near normal levels. These are illustrated in Figure 3.1 (over). They include the systems responsible for physiological homeostasis (in the brainstem and hypothalamus) which are necessary for continued survival; also, people with profound handicap have a sleep cycle (though it may be disturbed) and they exhibit remarkably consistent rhythms in their daily behaviour (Lewis, MacLean and Johnson, 1981) and in their limb movements during interaction (Burford, 1989). On a higher level, most show the capacity for at least some training, and occasionally individuals show remarkable feats of spontaneous learning. Memory systems appear to be functional to at least some degree, and behaviour showing recognition of familiar people is often a daily occurrence. Also, the systems in the brainstem and limbic system which form the core of emotion and communicative expression also appear to be largely intact. People with profound handicap certainly appear to possess emotions and have some form of working facial expressive system. This aspect of behaviour is examined in more detail in Chapter 4.

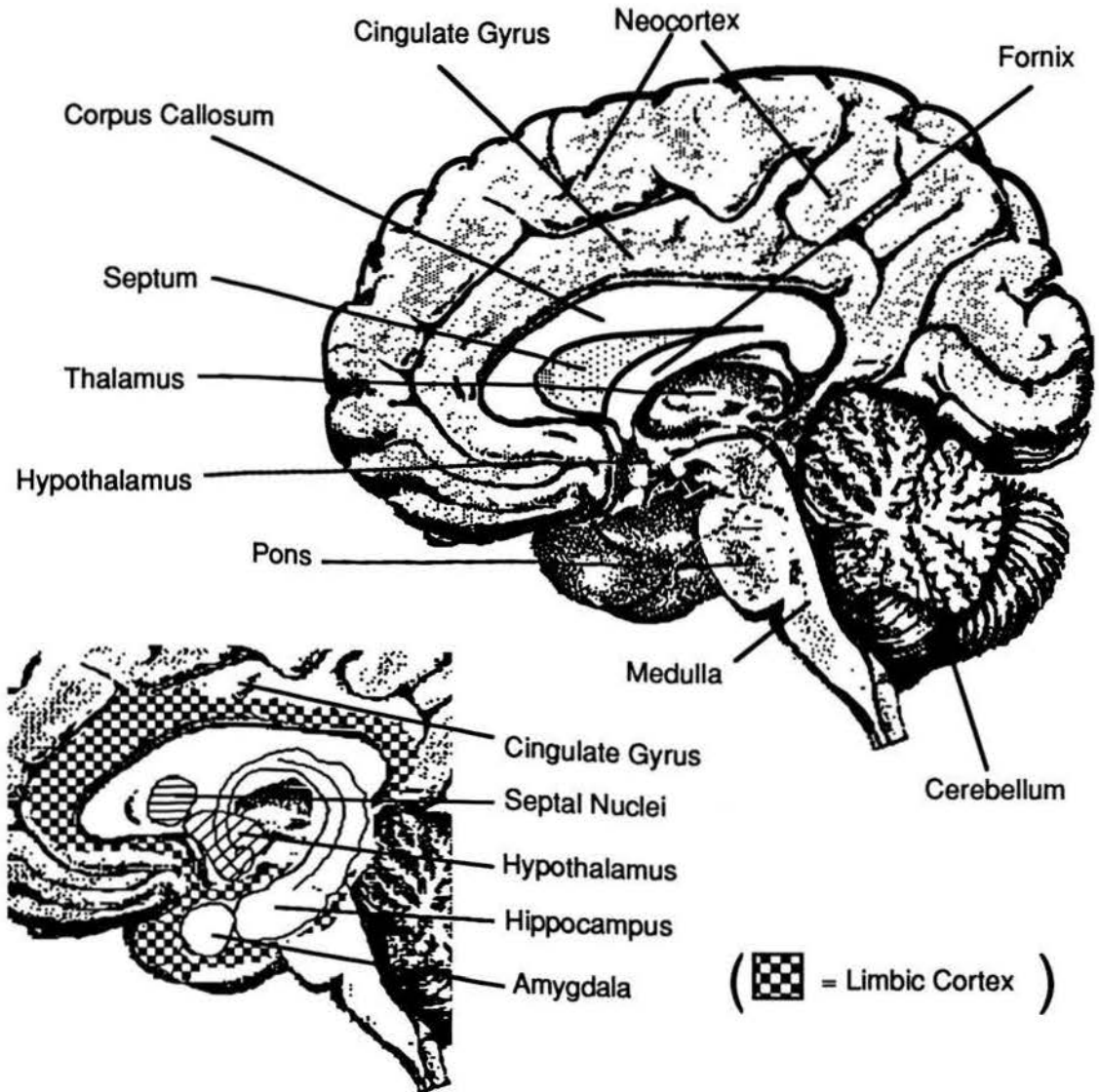


Figure 3.1 Medial View of the Right Half of the Bisected Brain.

Figure 3.1 shows the most important regions of the brain. The detail from this figure shows the brain structures involved in the Limbic System. Not shown are the Basal Ganglia, several masses of subcortical nuclei deep in the cerebral hemispheres which are important motor control centres.

The Limbic System is primarily concerned with the emotions and with memory and is made up of several structures. Sites have been identified which appear to be specifically involved in such sensations as pleasure, pain, lust, anger, and with attachment. Damage to regions of the Hippocampus have been shown to disrupt memory systems.

The Reticular Formation, deep in the Pons and Medulla, is responsible for physiological and metabolic homeostasis (which also involves the Hypothalamus), arousal, sleep, respiration, and pain, and is involved in the perception of surprise and in orientation. Subcortical areas in the Brainstem, particularly the Cerebellum, are also concerned with motor control, and with the processing and relay of sensory information, in which the Thalamus is the main gateway to the Cortex.

## *2.5 Assessment - Varieties of Tests and their Problems*

Recent years have seen a large increase in the number of assessments available for use with people with profound handicap. This section will concentrate on the few that are the most widely used, the most popular of which have, in fact, been around for some time.

Assessment is one of the major contributions of psychologists to the care of people with a mental handicap. In theory, an assessment has two main functions: administrative - providing an accurate description of a subject and predicting progress to allow service provision; and remedial - providing a profile of assets and deficits in an individual to guide specific training programmes and therapy, and objectively monitoring progress. Until recently, assessments claimed to perform both functions, and were criticized for their failure to do so (Clarke and Clarke, 1974).

Two theoretical approaches have guided most assessments: psychometric, which may employ developmental scales, and Piagetian, based on Piaget's theories of human cognitive development (an outline of which appears in Appendix II). Less used is the criterion-based approach, which uses a check-list for behavioural assessment and provides a summary profile of the behaviours an individual possesses. A recent innovation has been the development of specialized, complementary assessments which concentrate on certain areas of development.

The problems in using psychometric tests to define mental handicap have already been mentioned, and these also diminish the value of such tests in assessment. Standard psychometric tests for adults have been found unsuitable for the testing of young children for much the same reasons. This led to the development of tests specifically designed for use with children, the results usually being presented in the form of a 'developmental quotient' (the subject's development relative to normal development), rather than an intelligence quotient. Such tests have been extensively applied, without adaptation, to people with a handicap, and thus form the most common basis for assessment of children and adults with profound mental handicap.

Four psychometric developmental tests designed for measuring mental ability in the infant and young child are currently in wide use with people with profound handicap: Gesell's Developmental Schedules, Cattell's Infant Scale, the Griffiths Mental Development Scale and the Bayley Infant Scales. Of these, the Bayley Infant



Scales of Mental and Motor Development (1969) is the most standardized and the most widely used, particularly with people with profound handicap (e.g. Whiting and Krenna, 1986). It is designed for ages 2 to 30 months and consists of three independent components: a mental, motor and infant behaviour scale, though often only the mental scale is used. The majority of assessments carried out on people with profound handicap are by one or more of these four psychometric tests.

The psychometric approach has been criticized as limited in its practical applications to profound mental handicap. Predictive value, though higher with respect to people with profound handicap, is generally low, and psychometric tests have not been satisfactorily standardized on the handicapped population. Clarke and Clarke (1974) are amongst those who doubt the value of such tests in mental handicap. Inhelder (quoted in Hogg and Sebba, 1986) provided a summary of the most common criticisms of this approach in 1943. These include: that they focus on outcomes and products rather than cause; that they give an overall score without revealing areas of specific competence or deficit; and that they give no insight into the way behaviour is transformed at successive levels of mental development.

Inhelder sought an assessment based upon Piagetian ideas of development that would reveal the stage at which a child was operating and whether this level was behind that expected for the age. Woodward (1959) applied her approach to people with profound handicap and devised an assessment using six problems of differing complexity, based upon Piagetian tasks, that could be solved by abilities typical of Piagetian stages and thus could allow an estimation of the subject's level of functioning. This approach has been taken up several times since, the trend being (as with psychometric tests) to extend use of a test developed for a normal population to the handicapped.

The best known of the standardized Piagetian scales is Uzgiris and Hunt's Ordinal Scales of Psychological Development (1975), which has been recommended for use with people with profound handicap by several authors (e.g. Kahn, 1976). The scales use 'items' or tasks arranged in order of difficulty to cover key areas of sensorimotor development, such as permanence of objects. They assume an overall sequence of development but were conceived to be independent of Piagetian stages and of chronological age, and to allow description of an infant's psychological development without having to refer to a standardized group of infants.



This advantage is lost in the revision by Dunst (1980), who increases the practical application of the test by adding more items to create a finer progression and by placing alongside each item an Estimated Developmental Age (based on and correlated with a variety of psychometric tests) and the appropriate Piagetian stage. Hogg and Sebba (1986) note the utility of these scales with people with profound or multiple handicap and the ease with which they can be administered. Dunst (1980) claims that another advantage is that they take the highest pass as the level of development, assuming an ordinal scale of mental development. Although they do not give a global score in terms of mental age, as do psychometric assessments, it is possible to establish an M.A. equivalent in Piagetian assessments by reference to Piagetian stages.

The scales described above, psychometric and Piagetian, although all developed for use with normal infants, represent the vast majority of assessment procedures used with people with profound handicap.

An alternative to these tests of mental ability are assessments of social and adaptive behaviour, developed for use with people with a mental handicap. These are criterion-based assessments and should possibly be included under psychometric tests since many check-lists list skills in a hierarchical order based on a scheme of 'normative' development (though many do not, which is a cause of some confusion). Also, some check-lists give equal scores for each item although they may not represent equal steps in development, which can also be confusing. Amongst the most well known of these tests are the Vineland Scale and the American Association on Mental Deficiency Adaptive Behavior Scale (ABS) (Nihira, Foster, Shellhaas and Leland, 1974). These were not developed specifically for people with profound handicap, but they are often used with them.

The ABS consists of a comprehensive series of check-lists covering a variety of adaptive or appropriate behaviours (e.g. self-help skills) and some maladaptive behaviours, and can be used with a wide range of ability levels. It is completed by carestaff familiar with the subject and, though it is very complex and time consuming, it is particularly useful in the planning of training programmes. Other check-lists include the Portage check-list (Shearer, Billingsley, Frohman, Hilliard, Johnson and Shearer, 1972) which was originally designed for use with developmentally delayed children but is simple to administer and popular for use with subjects with a profound handicap.

None of the above behaviour scales have been developed solely, or even primarily, for use with people with profound handicap. Usually they have been designed for use with a wide range of levels of mental ability. Often, the size of the steps are too large to show any progress that may be being made by a student with profound handicap, and the blank spaces on the score sheet may create a very misleading impression.

Some scales have been developed specifically with people with profound handicap in mind. The Behaviour Assessment Battery (Kiernan and Jones, 1982) covers a wide range of the commonly covered areas, such as self-help and communication skills, and several less common ones which are arguably more relevant to people with profound handicap, especially skills which are important prerequisites for later development such as weight bearing and walking. It also consists of small steps in performance level, which allows for detailed assessment and assists in the planning of programmes. Unfortunately, administration is extremely time consuming. Similarly relevant check-lists include the Berewecke Check-list (Mansell, Felce, Jenkins and Flight, 1984) - developed for use in residential facilities and covering daily living skills - and The Next Step On The Ladder (Simon, 1981), developed for people with profound handicap who have additional handicaps.

There are several advantages in using criterion-based assessment and they are growing in popularity. They are readily available and easy to use, may be administered by carestaff who can observe the subject on an informal basis, and they provide a good, readily accessible framework for intervention. There are also indications that they correlate fairly well with more formal assessments (DuBose and Langley, 1977).

A recent trend is for the development of a number of supplementary assessments which are designed to complement other assessments rather than attempt to cover the whole range of abilities. These are usually criterion-based and can make an important contribution to accurate assessment. They also represent a different trend: the emergence of an 'interdisciplinary' approach, with caregivers, physiotherapists and psychologists all playing complementary roles. It should be noted, however, that while specialized assessment is valuable, global assessments such as the Bayley scales are still by far the most widely used.

Of the specialized assessments, many concentrate on the development of language and communication, examining abilities which tend to be far beyond those of

people with profound handicap. This problem is an important one, and one on which many of the other assessments (such as the Bayley scales and the Berewecke Checklist) have been criticized.

One approach to the assessment of language is to take into account the cognitive, social and linguistic factors which influence its development, and to consider language in terms of its pragmatic, social or communicative function. Snyder (1978), for example, has developed two scales concerned with 'declarative and imperative performatives', communicative acts whose definition is based on 'intentional/speech act theory'. Observation of these are carried out in the context of play. More directly applicable to people with profound handicap, however, would be an assessment which restricts itself to measures of non-verbal communication. There is, in fact, only one such assessment: Kiernan and Reid's Preverbal Communication Schedule (PVC) (1983). This encompasses a wide range of skills which form the background of non-verbal and verbal language development and whose possession is necessary in order to enter initial speech or non-verbal communication programmes. Assessment is divided into sections covering pre-communicative behaviour, imitation, non-verbal communication, and verbal communication. It is also structured to enable social function to be taken into account (e.g. seeking attention, negation and shared attention). This scale has been used explicitly to develop communication programmes and does not assess cognition directly.

Kiernan and Reid's assessment is an important innovation. One criticism, however, is that it takes the development of spoken language as the developmental goal and sees pre-verbal skills as a succession of steps to be completed. An alternative but complementary approach, and one that may offer new insights, is to consider early pre-verbal skills in their own right, as functional communication. This will be discussed fully in the next chapter.

This brief overview of the assessments used with people with profound handicap leads to the conclusion that no one instrument seems perfectly suited to the task. In fact, there is an overriding problem in the use of all assessments with people with profound handicap regardless of their type: the difficulty one encounters in obtaining reliable results from an individual with profound handicap who may perform completely differently on two different days, or who may even not allow himself to be tested. Even criterion-based assessments suffer from this problem: Felce et al (Felce, de-Kock, Thomas and Saxby, 1986), in an admirably honest paper, describe a study

which looked at changes in ABS scores in people with profound handicap following a move out of a large institution. They found that when a validity check was conducted which administered the ABS again after 24 hours, the scores for each individual varied so much that it was impossible to draw anything but vague conclusions from the research. Similar problems have been identified in cognitive tests by Wishart and Duffy (1989) in a long-term study of the instability of performance by Down's Syndrome infants and young children on the Bayley Scales.

There may be no solution to this problem, apart from simply being aware of the inherent variability in the performance of a subject who has a handicap, and being appropriately cautious of results. It is likely that there will always be some people with profound handicap who are impossible to test.

One partial solution would be to take into account ecological information about behaviour and patterns of behaviour change obtained from long-term carers. In practice, I found that many carers do not use formal assessments regularly, but rely instead on information of this descriptive kind, updated periodically when a carer notices a new or a changed behaviour.

## *2.6 Provision of Services for people with profound handicap*

In Britain and the U.S. the last two decades have seen the legal status of people with profound handicap change dramatically. They now have a right to an education and - in the terms used in U.S. law - access to 'the least restrictive environment' (Sontag, Burke and York, 1973). This approach can best be summed up as a 'community care' approach - people with profound handicap are to live and be educated out of the large custodial institutions and in the community.

*Education:* There is a large body of literature on education which it is outside of the scope of this review to mention. It is worth noting, however, the dispute between those researchers who argue that people with profound handicap are 'uneducable' and, therefore, not able to benefit from an education (Kauffman and Krouse, 1981), and those who point to numerous examples of their ability to learn (e.g. Stainback and Stainback, 1983), in some cases even after many previous attempts at teaching have failed (Ulciny, Thompson, Favell and Thompson, 1985).

*Vocational planning:* Again, there is a body of literature in social work relevant to this area and I will not go into any detail here. Generally, there are many problems in vocational planning for people with a mental handicap, especially for people with profound handicap (Wehman, Kregel and Seyfarth, 1985).

*Residence:* Provision of residential services has been extensively researched, and some of this research - particularly studies which have examined changes in interaction - is relevant to this thesis. Generally, such studies have agreed that residence in the community is better than residence in an institution, though some feel institutions may still have a role to play (Martin, 1974). A problem, however, is that whereas the benefits of community living are fairly obvious for the less handicapped, they are much harder to pin-point for people with profound handicap. Several studies have usually compared smaller residential homes in the community with institutions and measured the adaptive behaviour (sometimes including interaction) and problem behaviour of the residents, and occasionally the care practices of the staff. The study by Rawlings (1985a,b) is typical. A time sampling procedure was used to record the behaviour of the resident and the staff. Coding for the resident was a choice of: engaged, stereotyped, inappropriate and neutral behaviour or combinations of these; for the staff: passive functional care, active functional care or social contact. Rawlings compared ambulant subjects with severe or profound handicap who were living in hospitals or in group homes. She found no difference in self-help skills or amount of stereotypy, but that residents of the group home were more often engaged in constructive tasks, though the overall percentage of engaged activity was remarkably low. She also found that there were many more social contacts between staff and residents in the group homes.

The most interesting finding of this study was that the geographical location of the home did not seem to matter at all, the crucial factors being staff ratios (higher in the group homes) and - most important of all - the resident-oriented philosophy of the homes, and the flexible behaviour of the staff there, which allowed them to spend more time actively engaged with the residents. In fact, Rawlings found large changes in different hospital wards when staff adopted a similar, resident-oriented approach.

Similar studies by Close (1977), Witt (1981), O'Neill et al (O'Neill, Brown, Gordon and Schonhorn, 1985) and Felce, de-Kock and Repp (1986) have looked at residents transferred from institutions to small group homes and reported significant increases in self-help skills and the amount of interactions with staff. A comprehensive



study by Felce et al (Felce, de-Kock, Thomas and Saxby, 1986) compared the development of adaptive behaviour over 18 months in subjects with severe or profound handicap living in institutions, group homes or with families, and found greater progress in the group homes, though they admit that their method of testing (the Adaptive Behavior Scale) was not reliable enough for a detailed study. The conclusions of these researchers are similar to those of Rawlings: that the behaviour of the staff is a crucial factor. These conclusions receive further support from a study by Silverman et al (Silverman, Silver, Sersen, Lubin and Schwartz, 1986) who unexpectedly found greater adaptive behaviour changes in a small institution than in a group home, when that institution implemented a systematic programme of care and training. Other factors which may be playing a part have been suggested by Felce, de-Kock and Repp (1985) who note the increased availability of materials, and by Shrubsole and Smith (1984) who report the effect of a simple improvement in the environment, finding improved behaviour after a refurbishment of a hospital ward. Other studies (e.g. Ohwaki and Stayton 1978) have simply documented the long term effects of living in an typical institution. These confirm fears that a decrease in adaptive skills occurs, the size of which correlates with length of institutionalization.

It seems unequivocal that even the most handicapped person can benefit from a move to a well run, small group home. In fact, the only note of caution is sounded by Heller (1982), who showed that the process of moving - even if it is into the community - results in a deterioration in health and decrements in positive behaviour in children with severe or profound handicap. These effects may be short term and outweighed by the advantages of moving to a suitable residence, the provision of which has been made easier by the research findings described above.

## *2.7 Aspects of Care*

*Staffing and care programmes:* Many day to day aspects of care have changed considerably in recent years. Only those that have relevance for affective and communicative behaviour will be outlined here.

The staff-to-resident ratio has obviously been seen as important, but, surprisingly, Mansell et al (Mansell, Felce, Jenkins and de-Kock, 1982) found that if the ratio is increased, the amount of time each individual staff member spends with the residents decreases. Obviously, a different organization of staff is needed as well. One way to do this is to give additional training to staff on how to behave - i.e. encourage



them to interact with their charges. Using a training package, prompts and feedback, studies by Burch et al (Burch, Reiss and Bailey, 1987) and Reid et al (Reid, Parsons, McCarn, Green, Philips and Schepis, 1985) have had some success with such an intervention in a residential facility and a school, respectively.

Alternatively, another approach is to reorganise the roles given to staff (e.g. Byrd, Sawyer and Locke, 1983). Amongst the most promising of these suggestions are the use of a 'unit play manager' whose job it is to stimulate and maintain play with all children in a room, leaving other members of staff free to spend time in one-to-one activities (Spangler and Marshall, 1983); and similarly a 'room manager' who stimulates purposeful activity (Mansell, Felce, de-Kock and Jenkins, 1982). Green et al (Green, Canipe, Way and Reid, 1986) and Sturmey and Crisp (1984) have looked at the effectiveness of combinations of some of the methods mentioned above, with encouraging results.

Other researchers have investigated ways to improve care by improving the environment. Spreat (1987) found that the introduction of a modular play unit with different response-activated devices increased the interacting behaviour of children with profound handicap and their staff; Murphy and Zahm (1978) found improved ward conditions reduced problem behaviours in people with profound handicap; and Cleland, Swartz and McGavern (1977), on a larger scale, have suggested improvements in the architecture of institutions.

Most of the research which has had a direct bearing on the care of people with profound handicap are training studies, which will be discussed later, but some studies have made general suggestions for improvements in care practices. Feeding is extremely time consuming and staff often have difficulty finding time for interactions (Ohwaki and Zingarelli, 1988), but Hendrikson et al (Hendrikson, Kay, Akkerman, Speggan and Thompson, 1985) suggest that one way to improve this situation is by reducing the maladaptive behaviour seen in people with profound handicap at mealtimes by simply reducing the numbers dining together.

*Therapies:* Recent years have seen a re-evaluation of the use of therapies with people with profound handicap, including music therapy (Oldfield and Adams, 1983), art therapy (Eydenberg, 1986) and, recently, the new practice of movement therapy (Burford, 1986), which is concerned with developing very basic non-verbal communicative abilities. Movement therapy will be discussed in the next chapter.

*Leisure activities:* An often ignored aspect of caring for people with profound handicap is the provision of leisure activities. This is a challenging area in which to put into practice the philosophies behind care in the community and Schleien, Wehman and Kiernan (1981) have argued convincingly for age appropriate leisure skills to be taught.

*Pharmacology:* Use of drugs is a major facet of modern care for people with profound handicap, medication being prescribed for the control of epilepsy, the management of behaviour problems, problems in sleeping, and occasionally for suspected psychiatric problems. Since doses of medication for people with a mental handicap are higher within institutions than in the community (Rawlings, 1985a), medication levels may change in the future. At the moment, however, the numbers of people with profound handicap receiving medication are disturbingly high.

Fox and Westing (1986) looked at prescribing for people with profound handicap and found 53% were on medication, usually anti-epileptic or tranquillizers. Fischbacher (1987) has described prescribing in a typical mental hospital. He found that 61.5% of residents were on anti-convulsants (over 37% were on a combination of different anti-convulsants); 33% were on anti-psychotic or related drugs; 4.2% were on tranquillizers; and 2.6% were on anti-depressants. He notes that many drugs with known undesirable side effects were still being prescribed. Many hospital residents may have been receiving medication for years without review and Fischbacher (1982) has attempted a reduction in the level of anti-convulsants in 36 residents, finding that 20 were able to have one drug withdrawn and show no ill effects at all.

Recently, serious concerns have been expressed about the use of tranquillizers in the general population, and these worries are beginning to be extended to people with a mental handicap. This issue is becoming especially relevant as more and more individuals are moved out of hospital wards and into the community. Medication may be a factor in many aspects of the behaviour of people with profound handicap, but very few studies comment on this, the vast majority giving no details of the medication of the subjects. The medication taken by the subjects used in this thesis was noted, and an attempt was made to determine the effects this may have had on behaviour. This is discussed in detail in Chapter 5.

## *2.8 Cognition and Behaviour Modification*

By far the most important aspect of cognition in people with profound handicap is their limited capacity to learn. Failure to learn is an obvious, important characteristic of people with profound handicap: they show an extremely limited ability to acquire even the most basic self-help skills, such as dressing, eating, and toileting. This has led to some debate about their suitability for education. What knowledge we have about their capacity to learn comes in the main from behaviour modification studies. Although the majority of such studies have used subjects who are more able, there are many that appear to have used a behaviour modification paradigm with people with profound handicap. I will not consider these in any detail, but will concentrate on reviews of their effectiveness and what this can tell us of the ability of people with profound handicap to learn.

Behaviour modification is a technique that has undergone considerable development in the last twenty years and a great many studies have reported varying degrees of success in a variety of training programmes, ranging from the control of self-injurious behaviour to training for several self-help skills (Whitman, Scibak and Reid, 1983).

Some have argued that these studies have proved that even people with the most severe handicaps are capable of learning and that it should be accepted that all children can learn when provided with appropriate forms of instruction (Baine, 1986). Evidence for this comes from a number of reviews, most notably Stainback and Stainback (1983) who, unusually for this area, restricted their review to only those behaviour modification studies which have used subjects with profound handicap. They were able to cite examples of successful learning in studies which had trained motor skills, self-help skills, social and language skills, and which had reduced maladaptive behaviour. They emphasize that in these cases people with profound handicap have been taught meaningful behaviours. They are cautious about making claims that all people with profound handicap can learn, but make a strong case for seeing the past two decades as a period of great progress in this area. Above all, they suggest that there is no reason as yet to presume that any individual with profound handicap cannot learn, and that it seems advisable to keep a "positive attitude about the educability of profoundly retarded persons" (p.97).

There have been a number of similar reviews. Berksen and Landesman-Dwyer (1977) looked at research conducted with people with severe and profound handicap between 1955 and 1974, and note the tremendous effect on the perception of the educability of this group which the growing number of successful behaviour modification programmes have had. Presland (1982) has summarized the results of several studies in which people with profound handicap have been taught a variety of gross motor skills. LaGrow and Repp (1984) have looked at studies that have used behaviour modification procedures to suppress stereotypic responding (usually body rocking) and found many that appeared to be effective. Singh and Winton (1983) reviewed studies which attempted to train people with severe and profound handicap in social skills such as cooperative responding in play, conversational skills, and non-verbal physical or close-proximity interactions. They found that many studies appeared to have some success, but that few tested or trained for generalization, and few included any maintenance or follow-up procedures.

Similar reservations are given by Konarski and Diorio (1985) in their review of 87 studies which attempted to train self help skills in people with severe or profound handicap. The majority (67%) trained toileting and feeding skills, took place in institutions (63%), and used residential staff as trainers (69%). Few studies reported assessments of generalization, maintenance or social validity. They conclude that there is a real need for such studies to tackle these issues and to use different settings, trainers and behaviours, though they also note that more recently the quality of the scientific standards in the area has improved.

In fact, when such reservations are borne in mind, it is not altogether clear how successful behaviour modification techniques have been with people with profound handicap. Whitman, Scibak and Reid (1983) have reviewed the 280 behaviour modification studies using subjects with severe or profound handicap published in America between 1962 and 1979. Of the 280 studies, 26% involved people with profound handicap, 15% both people with profound and people with severe handicap. Incredibly, 8% did not specify the level of handicap, making them, for the purposes of this thesis, quite useless. Most studies looked at self-help skills, especially toileting. Few studies looked at social skills.

Although many of these papers claimed significant achievements in modifying behaviour, the conclusions of Whitman et al are not complimentary. They point out that "systematic attempts to test the general utility of particular techniques with subjects

who reflect the total range of deficiencies characteristic of severe and profoundly retarded persons were non-existent" (p. 383). In most of the studies, there was neither a random selection of subjects, a wide cross-section or a large sample. They felt that an unfortunate but distinct possibility was that researchers were selecting the most able of the population to be subjects, thereby destroying external validity. In addition, they found no longitudinal designs, most studies being content to look at purely short term effects, and only one attempt to monitor the implementation of training procedures. There was also no attempt by any study to look at the generalization effects of the training, though failure to generalize may be a crucially important characteristic of learning in people with profound handicap and has been noted by several investigators (e.g. Kelman and Whitely, 1986).

Thus, although some success in using behaviour modification techniques with people with profound handicap have been reported, with learning typically taking a very long time, until the techniques are proven on a representative sample of people with profound handicap and subjected to a proper follow up, it is hard to evaluate the results. Konarski and Diorio (1985) suggest that this may now be happening, but firm conclusions cannot yet be made.

Behaviour modification programmes are often used as evidence for the learning ability of people with profound handicap and to refute the view that they are 'incurable and ineducable', and in fact very little other evidence is available. There is some doubt, however, that behaviour modification studies really tell us anything about the learning capacity of people with profound handicap at all. Ellis et al (Ellis, Deacon, Harris, Poor, Angers, Diorio, Watkins, Boyd and Cavalier, 1982) have argued that successes in training "have often involved limited behaviour in restricted settings, observed for short durations of time with little follow-up or information on the durability of the behaviour" (p.187), and that such procedures do not actually test learning capacity.

Other studies providing information on the cognitive capacity of people with profound handicap are, however, extremely rare. Recognition memory - and the ability to detect patterns - has been demonstrated in people with profound handicap by three studies: Shepard and Fagan (1981), who used different visual patterns (including faces), Butcher (1977), who used colours and faces, and by Ellis and Boyd (1982), who also used faces. The ability to perceive depth has been found in only 39% of a





sample of people with profound handicap by Garcia et al (Garcia, Cleland, Rago, Wayne and Swartz, 1974).

A study by Harris (1980) is one of the few studies of learning conducted in a laboratory. He found some evidence for learning in a sample of people with profound handicap given two-choice discrimination problems. A comprehensive study by Ellis et al (1982), however, is more conclusive. It provides an interesting comparison to behaviour modification studies and actually tells us much more about the cognitive capacities of people with profound handicap.

Ellis et al conducted a strictly controlled laboratory study of simple discrimination learning, memory, and transfer in subjects with mild, severe or profound handicap under near-optimal conditions. They found that people with profound handicap learned and re-learned problems far more slowly, forgot more (even when tested an hour after training), and showed no positive transfer of learning. They also found very wide individual differences with one individual with profound handicap performing as well as the less handicapped subjects whilst two others showed no learning at all, and large fluctuations in performance from day to day. Overall, there were major differences between subjects with profound handicap and subjects with other levels of handicap, and Ellis et al note that many of the techniques of training had to be modified for the profound subjects before they could take any part in the study. They conclude that most people with profound handicap can learn, although this may take considerable time and generalization does not occur. They also suggest that there may be a subgroup within the profound population who will not show any learning at all, but admit that it is impossible to be certain unless all conceivable methods of training are attempted.

This study, taken with the positive results from the more creditable of behaviour modification studies, suggests that there is an aptitude for at least some learning in people with profound handicap, and that many have some sort of functioning memory system. Where progress in learning has been made it is typically very slow, though it is often, it must be said, subject to many factors (such as the availability of staff and the consistent implementation of a training programme) which are outside of the subject's control. Bailey (1981) has warned against the enthusiasm for behaviour modification blinding us to its problems, and to its alternatives, such as sensory stimulation programming (Glover and Mesibov 1978), which may produce similar, or greater, increases in the quality of life.



The attitudes of carers to behaviour modification studies may be somewhat different from those of researchers. Many express a jaundiced view of such studies and believe that typically, psychologists begin a behaviour modification programme, achieve spectacular results, and then move on, leaving the staff to carry on the work. Mostly, the programme and the learnt behaviours are slowly forgotten. Hopefully, as the size of facilities and organization of staff changes, so will these experiences.

An interesting contrast to the learning reported in training studies are cases reported by carers of day-to-day instances of remarkable feats of long term remembering, and the numerous anecdotal examples of isolated, extraordinary feats of spontaneous learning. This is a curious paradox to which I will return later in this thesis.

It is difficult to summarize research on learning in people with profound handicap. Behaviour modification studies have reported a number of successes, though they typically have severe methodological problems which make it difficult to draw conclusions from them. Nevertheless, in the last few decades they have significantly altered for the better the way we think about and care for the more handicapped (Berkson and Landesman-Dwyer, 1977). The few laboratory tests of learning suggest that, in the right conditions and given enough time, most people with profound handicap can learn, but we do not yet know enough to decide if any individual with profound handicap cannot and will never learn. In fact, we may never be certain of this - there is always the possibility that a new technique will succeed (Ulciny et al, 1985). A more fine grain analysis of learning in people with profound handicap may help (Hogg, Foxen and McBrien, 1981), but meanwhile it seems morally and scientifically advisable to give the opportunity to learn to every person with profound handicap.

## *2.9 Behaviour and Behaviour Problems of people with profound handicap*

*Descriptions of behaviour:* Most research which has looked at the behaviour of people with profound handicap has done so only as part of a behaviour modification study. Another large group of studies has looked at the effects of changes in the environment, such as a move into the community, and used behaviour as a dependant variable, in which case the level of analysis is typically restricted to a classification of behaviour as adaptive, maladaptive or neutral. In contrast, studies which concentrate on describing

the behaviours of people with profound handicap in detail are comparatively rare. MacAndrew and Edgerton (1964) published an important early paper on the typical day-to-day behaviours of institutionalized people with profound handicap. Since then, Wills (1973) has written a more recent but limited and unsatisfactory book on the same.

A series of naturalistic studies of behaviour have been reported by Barton and his colleagues (Barton and Repp, 1981; Barton, Brulle and Repp, 1982; Repp, Barton and Gottlieb, 1983), which found that presence of other people with profound handicap and group size had no effect on behaviour, but presence of a staff member increased interaction with the environment. Similarly, Landesman-Dwyer, Berkson and Romer (1979) have looked at social behaviour and found that whilst hospital residents with mild handicap engaged in social behaviour when with others (usually in dyads), and neutral behaviour when alone, residents with profound handicap showed no such changes. They did report that people with profound handicap were capable of some social behaviours, however, a finding confirmed by Altman (1972), who looked at the response of people with profound handicap to a common form of social stimulation - the handshake - and found that 77% responded correctly, and by the finding of Bailey et al (Bailey, Tipton and Taylor, 1977) that people with profound handicap respond to a threatening stare.

Several studies have attempted to describe general patterns of behaviour in people with profound handicap. Rates of activity have been found to follow an ultradian (less than 24 hours) rhythm (Lewis, MacLean, Johnson and Baumeister, 1981), and to respond to changes in environmental noise levels (Gelblum, 1984). Vyse, Mulick and Thayer (1984) have used naturalistic observation to examine the behaviour of children with profound handicap in the classroom, finding that during instruction periods they spent only half of the time 'on task'.

An important source of information has come from studies that have taken an ethological approach, applying methods used in studying animal behaviour to people with profound handicap. Using techniques developed to observe the behaviour of chimpanzee colonies, strong evidence for territorial behaviour and a distinct dominance hierarchy amongst institutionalized people with profound handicap has been presented by Rago and Cleland (1978b) and Paslawskyj and Ivinskis (1980), who studied frequency and initiation of touching, and Rago (1977) who looked at gaze aversion. Territorial and dominance behaviour appears to be remarkably stable

(Rago, 1978). One direct result of this research is the finding that increasing the living space of institutionalized residents by 29% has a significant beneficial effect, reducing the amount of aggressive behaviour (Rago, Parker and Cleland, 1978). Similarly, Aldrich and Doll (1931a) used tasks involving tool use first developed for chimpanzees (such as stacking boxes to use as a support to reach a reward) and found that although people with profound handicap could perform some of these tasks, their ability fell somewhere between the apes and human infants. More recently, Cleland, Rago and Mukherjee (1978) have described several fascinating examples of spontaneous tool use in people with profound handicap.

Pechacek et al (Pechacek, Bell, Cleland, Baum, and Boyle, 1973) looked at self-recognition in people with profound handicap by adding paint to the forehead of subjects and then presenting them with a mirror. They found no self-recognition, nor could a later study (Harris, 1977) train for it. Garcia et al (1974) found depth perception in less than half of the people with profound handicap in their study. Thus, studies of tool use, self-recognition and depth perception seem to place the level of functioning of people with profound handicap below that of chimpanzees and 7-month-old human infants. It must be stressed, however, that so far few studies of few topics have been made, and - most importantly - all of the subjects in these studies were institutionalized.

One area which throws some light on the preferences and the behaviour of people with profound handicap is the identification of effective reinforcers used in training - i.e., what things people with profound handicap like. It can actually be very difficult to establish a preference hierarchy (Rotatori, Fox and Switzky, 1979) and there are extremely wide individual differences (Saperston, Chan, Morphew and Carsrud, 1980), but visual, auditory, vibratory, and musical stimulation, food, and social reinforcement have all been used effectively with people with profound handicap.

*Behaviour problems:* That people with profound handicap demonstrate a variety of persistent maladaptive behaviours is well-known (Reid, Ballinger and Heather, 1978; Reid, Ballinger, Heather and Melvin, 1984). These include feeding disorders (e.g. persistent regurgitation, pica, bed wetting); undressing; public masturbation; aggressive behaviour; self-injury; and stereotypy. These last three have received the most attention in the literature.

Disruptive or aggressive behaviour appears to be fairly common in people with profound handicap. Studies are invariably based in institutions, however, and Cleland, McGavern and Case (1976) believe that rates of disruptive behaviour may be related to changes in staffing. Interestingly, they also point to the existence of a large subgroup who are active - and disruptive - only at night, and suggest that they may have a different daily cycle. Treatment of disruptive behaviour is almost always by behaviour modification methods (Matson and Gorman-Smith, 1986).

Self-injurious behaviour ranges from biting fingers to causing permanent physical damage by head banging. Precise definitions are difficult because there is still much that is not known (Schroeder, Mulick and Rojahn, 1980). Prevalence data are therefore tentative. Rojahn (1984) estimates prevalence in people with severe and profound handicap at 66%; Griffin et al (Griffin, Williams, Stark, Altmeyer and Mason, 1984) surveyed 10,000 people with mental handicap in institutions and found a prevalence rate of 13.6%, of which 89.9% were people with severe or profound handicap; Oliver, Murphy and Corbett (1987) found that 19% of 616 people with mental handicap performed a serious self-injurious act at least once an hour, and that these were more likely to be people with severe or profound handicap.

The causes of self-injurious behaviour are not known, but it seems to be a way of obtaining stimulation. Iwata et al (Iwata, Dorsey, Seifer, Bauman and Richman, 1982) point to the importance of features of the physical and social environment and Cleland (1979) emphasizes the role of institutionalization, but the behaviour is also seen in people with profound handicap living at home in stimulating environments.

Intervention is most often by behaviour modification (Gorman-Smith and Matson, 1985). Treatment usually relies on operant conditioning procedures, including the use of punishment (e.g. Singh, Dawson, and Gregory, 1980), but their effects tend to be temporary and fail to generalize (Schroeder, Mulick and Rojahn, 1980). Other approaches have included the use of sensory integrative techniques (Wells and Smith, 1983) and self-protective devices (Rojahn, Schroeder and Mulick, 1980), both with limited success.

Stereotypy (a repeated movement such as body rocking) is also hard to define precisely, but is widely present in people with profound handicap. Dura et al (Dura, Mulick and Rasnake, 1987) found at least one stereotypic behaviour in 34% of the non-ambulant people with profound handicap surveyed. It has been rated by teachers

the most difficult behaviour problem to manage (Wehman and McLaughton, 1979).

The antecedents of stereotypy are unknown. Sturmey, Carlesen, Crisp and Newton (1988) have successfully used the procedures developed by Iwata et al (1982) to show the importance of the environment, though Lewis (1984) reports that the tempo of stereotyped behaviour is independent of changes in a tempo produced in the environment. Buyer et al (Buyer, Berkson, Winnega and Morton, 1987) have found two components that are important to the person producing stereotyped behaviour: the stimulation itself, and having control over it.

Several interventions have been used to try and reduce stereotyped behaviour (Spindler-Barton and Broughton, 1980), including operant procedures (e.g. Barton, Repp and Brulle, 1985); the instruction of alternative leisure activities (Mace, Browder, and Martin, 1988); and teaching sensorimotor skills (Nakamura and Takahashi, 1982).

As can be seen from this review, our understanding of the behaviour of people with profound handicap and its motivation is very limited. The number of studies actually observing and describing behaviour is exceptionally low, though an ethological approach has produced some interesting findings. Most research, however, has focussed on the treatment of identified behaviour problems by behaviour modification techniques.

### *2.10 Language, Communication and Interaction*

An aspect of crucial importance in many people with profound handicap is the complete absence of spoken or signed symbolic language. This failure of language development may be considered an aspect of cortical dysfunction. How far there is a specific dysfunction of the language production area (Broca's area), the comprehension area (Wernicke's area), or other associated areas, or a general dysfunction of the brain areas responsible for all cognitive functioning is not known. It is also uncertain to what extent an individual with profound handicap can be trained in language skills.

*Attempts at teaching language:* The relative contributions of environmental and cognitive factors to the normal development of language, and the relationship between



language and cognition, are somewhat controversial topics in psychology. A helpful approach has been to look at language development in terms of its function, and in a social context. The roots of language lie in the relationship between infant and mother and the communication between them. A mutual responsiveness and sensitivity is reflected in the development of play behaviour which, in a normal attentive and responsive infant, begins from birth (Bullowa, 1979). This relationship is quite fragile, however, and can be upset by a problem in the behaviour of the infant or the mother (Fraiberg, 1979). In prelinguistic Down's Syndrome infants with severe mental handicap, for example, the same level of responsiveness to the mother was not found (Jones, 1977). Generally, in handicapped infants there is a danger that the attachment which should form between mother and infant will be delayed, dulled or absent (Blacher and Meyers, 1983). Similar research with infants with profound handicap is extremely rare, though Blacher (1984) has looked at infants with severe and profound handicaps with their mothers and found that some form of attachment behaviours were present in even the most handicapped, though these were much less complex and more variable than those seen in normal dyads. Similarly, Glenn and Cunningham (1984) have found that 8-9 month old infants with severe and profound handicap enjoyed similar nursery rhymes to normal infants, and preferred those with familiar words.

Recently, the focus has been on intervention to improve the quality of the relationship between the handicapped infant and the mother (Kysela and Marfo, 1983). Typically, this involves structuring a game which a mother plays with her developmentally delayed infant (e.g. Hodapp, Goldfield and Boyatzis, 1984). There are no such studies with children with profound handicap.

The goal of much early intervention with children with a mental handicap is to increase the chances of language development. For this to succeed, however, the interaction with cognitive development has to be considered. Several researchers have studied this process in normal development, many emphasizing the cognitive pre-requisites of language. Bates et al (Bates, Benigni, Bretherton, Camaioni and Volterra, 1977) see these pre-requisites as the symbolic thought of stage six of Piaget's theory, shown by 18-24-month-old infants. These developments are preceded by the non-verbal gestures arising from tool use at a stage earlier. If this is the case, it is significant that many people with profound handicap demonstrate no capacity for symbolic thought or fantasy play.



Some studies have attempted to provide training for the people with profound handicap on the cognitive pre-requisites of language. Kahn (1984) has taught object permanence and means-ends relationships in addition to language training, with some success. Sternberg, McNerney and Pignatore (1985) believe that the separation of self from the environment is an even more basic pre-requisite and have designed a training programme for this based on co-active imitation.

Alternatively, some have attempted to teach pre-linguistic behaviours directly (Gola, Holmes and Holmes, 1982). Sternberg and his colleagues (Sternberg and Owens, 1985; Sternberg, McNerney and Pignatore, 1987) have trained pre-language signalling behaviours in people with profound handicap, seeing this not as necessarily leading to vocal language, which they believe may be beyond their capacities, but as a method of communication in its own right.

The attempts to encourage the development of language in people with profound handicap described above appear promising, but a different approach has been to teach language skills using behaviour modification programmes. These often have the same faults (especially lack of generalization and follow up) as such programmes in other areas, as outlined earlier. In addition, many of the subjects appear to represent the more able of those individuals with profound handicap, especially those studies which have attempted to train vocal skills. In the study by Barton (1973), for example, the three subjects are described as having self-help skills and being capable of participating in simple conversation *before* the study. Although a variety of methods for language teaching have been described (Davis, 1978), and some studies do claim to have improved the speech of "marginally vocal" subjects with profound handicap (Brody, Thomas, Brody, Kuchera, 1977), there remain some doubts that these procedures are effective with less able individuals, though some studies have successfully attempted to teach receptivity to verbal instructions using operant methods (e.g. Booth, 1978; Striefel, Bryan and Aikins, 1974). Generally, however, teaching sign systems appears to be more effective (Kahn, 1977; 1981).

*Teaching non-verbal communication systems:* The majority of studies attempting to train communication skills in people with profound handicap have looked at training non-vocal communication systems, and there are now several important studies in this area. Lloyd and Karlan (1981) have reviewed many of the communication systems available, Williams (1980) has summarized the operant training methods most often used, and Kiernan (1981) has presented a strategy for future research. Generally,

training programmes use either a manual sign system (using hands or fingers) or a symbol system (where different shapes represent objects). Both systems requires an act of recognition, discrimination, and a simple motor response, but Hodges and Schwethelm (1984) have argued that the first may be more effective.

Hobson and Duncan (1979) taught subjects with profound handicap signs for several pictures, some of which were retained after 2 months. Studies by Richardson (1975), Ferguson (1975) and Lombardino and Kaswinkel (1983) have taught some manual language signs to small groups of people with severe and profound handicap. Carrier (1974) used a training study using a symbol system which he reported was successful with most severe and profound subjects. Haskett, Bost, Hawkins and Hawley (1977) attempted to train 9 people with profound handicap on a very simple symbol system, having some degree of success with half of the subjects.

Deich and Hodges have conducted a well known study (Deich and Hodges, 1977; Hodges and Deich, 1978; Deich and Hodges, 1982), using a system based on that of David Premack (Premack and Premack, 1972) designed for teaching language to a chimpanzee. This consisted of small plastic tokens each representing a word which were placed on a board to make 'sentences'. The study attempted to train a number of institutionalized children, including a group of non-verbal children with severe or profound handicap who had expressive language skills ranging from grunts and clicking sounds to a few who used words. They note that two children were unable to be trained due to behaviour and motor problems.

The results showed that after 6 months most of the children achieved at least a minimal amount of progress, but that learning in the low functioning group was extremely slow and teaching had to be split up into small steps. This group also suffered from several unique problems: they could usually match a symbol to the object, but did not understand the reverse, which had to be taught separately. They also showed no transfer of learning to a new set (shift learning), so symbol-object and object-symbol had to be taught for each item. They had great difficulty in learning verbs and none mastered two word sentences.

Aspects of this study recall the problems repeatedly met with behaviour modification studies: few details are given of the subject's characteristics, medication, or additional sensory and/or physical handicaps (apart from the severe motor problems of one subject who was excluded for this reason). It is also worth noting that the low

functioning group demonstrated problems in attention and that a minority proved untrainable. The most important point, however, concerns the nature of the communication system. Looking at the process from the point of view of what was learnt, it seems that the subjects could as easily be described as simply learning cyphers, and not a language system. In this study, as in the others, there is no evidence of generalization or the application of very basic linguistic rules. It is certainly far removed from our understanding of true language, even of the level of 'language' claimed for chimpanzees.

It is, I think, worth noting that many of the non-verbal systems are derived from studies which claim to show language learning in chimpanzees, and to ask whether the same criteria used to criticize the chimpanzee studies ought to be used here. Terrace et al (Terrance, Petitto, Sanders and Bever, 1979; Terrace, 1979) found, for example, that seemingly impressive sentences produced by chimpanzees were, in fact, simple repetitions. Even the 'words' used in most two 'word' sentences appeared, on closer examination, to be unrelated to each other. When video tape of sessions were studied, it also became clear that the chimpanzees' utterances were merely copies of signs just previously made by trainers. More importantly, the nature of the language used by chimpanzees was drastically different from that of human children: the amount of information conveyed in sentences remained small regardless of growth in the size of the vocabulary of signs; communication systems were not acquired spontaneously by any chimpanzee and seem, on the whole, to be used as a trick to obtain food or attention. Such a critical analysis of results has not been applied to any study which has attempted to train sign systems to people with profound handicap .

Whether these criticisms are proven valid or not, it is clear that learning a non-verbal communication system at a level as basic as that seen in these studies does not yet constitute learning a language: Communication can be defined as the passing of a piece of information from one living animal to another; language is the consistent application of a set of rules to combine arbitrary symbols which enables communication on a vastly increased scale. Language is also inextricably bound with cognition, informing and influencing the way we perceive, remember and think about the world around us; it is both a creative tool for thinking and part of the thinking process itself.

It is not clear how much progress people with profound handicap may make in learning a true language. Although there are problems in learning communication

systems as well, there seems to be strong evidence from the research discussed in this chapter that many of the subjects with profound handicap may be able to make significant progress in learning to make some communicative signs. If there is a possibility that people with profound handicap can learn a sign system to communicate, we have to balance the effort involved with the possible benefits, which may be very great, conferring an ability to communicate needs directly, for example. Therefore, although I have some reservations on methodological grounds and would like to see studies which monitor generalization, long-term follow up and spontaneous use, it seems desirable, in view of the possible benefits, that all of people with profound handicap have the opportunity to take part in communication training. My strongest reservation, however, is that the possibility of such training should not blind us to the importance of supporting the communicative abilities which they already possess.

*Studies of interaction and communication:* Formal studies of interactions involving people with profound handicap are extremely rare. Reading the literature, it is actually very hard to form any judgement about the abilities to communicate which people with profound handicap may have. Yet there is a clear consensus amongst parents and carers that they do communicate abundantly.

Most of the information available on interactions involving people with profound handicap has come from studies which have been primarily concerned with observing some other aspect of behaviour. A good example is offered by studies which have looked for differences between institutions and group homes in the behaviour of residents and staff (see section 2.6). Typically, they will use time sampling to see what proportion of time is spent on adaptive (e.g. self-help) and maladaptive (e.g. stereotyped) behaviours. Interactions with the staff are often counted in the first category. More often, they are held to be of interest only in assessing the behaviour of the staff.

The same trend has usually been followed by studies which appear to concentrate on interaction; most, in fact, have not looked very closely at the behaviour of people with profound handicap, and almost all have been confined to subjects living in residential facilities. Wright, Abbas and Meredith (1974) observed the interactions between 16 ambulant children with profound handicap and staff in a residential institution. Interactions were coded as positive (when the staff promoted independent behaviour in people with profound handicap); negative (promoting dependant



behaviour), or neutral (neither of the others, e.g. holding or cuddling). They found that interactions amounted to less than 7% of the time observed (240 minutes for each subject), and that the vast majority were initiated by the staff (only 2% were initiated by the children). They were most concerned with the type of interaction, however. The most frequent category was neutral, and they suggest that staff should be trained to initiate positive interactions.

In an early study looking at people with severe handicap, Veit et al (Veit, Allen, and Chinsky, 1976) studied resident-staff interactions using time sampling and a system which recorded a variety of the characteristics of the interaction and antecedent staff and resident behaviours. They found that 91% of the interactions were staff initiated, and that these tended to be physical/verbal commands, made during child care or ward activity periods. The vast majority of interactions contained no positive or negative affect. The residents initiated only 8.8% of the interactions which tended to be physical/verbal, occur in social play and were more likely to have positive affect.

More recently, Repp, Barton and Brulle (1981) looked at the interactions between staff and residents with profound handicap in both an institution and a small group home, but found interactions in only 10% of the time observed. When staff were instructing residents, they mostly used verbal commands which were not very effective, the most effective technique being physical assistance alone or in combination with verbal commands. A similar figure for the amount of interaction was found by Hermanson and Das (1977). They used time sampling to observe the interactions between non-ambulant residents with profound handicap and staff on 4 wards of a residential institution. Interactions were defined as an "activity directed towards a child by staff" and coded as non-verbal/verbal task related, or non-verbal/verbal non-task related (social). They found that staff spent on average 8% of time on social interactions, though there were large differences between wards. Severity of handicap did not influence the amount of time staff spent in interaction, though they spent more time (and played more) with residents who had better physical development. This last point is reinforced by a study of residents with severe handicap conducted by Dailey, Allen, Chinsky and Veit (1974) who found that, overall, staff spent only 1% of time in social interactions but that they spent more time - and interacted in a more friendly and positive manner - with residents who they perceived as attractive, likeable and intelligent. Comparable staff preferences were found by Reuter et al (Reuter, Archer, Dunn and White, 1980), who conducted a long term time-sample study of interactions in a residential treatment centre for clients with mild,



severe and profound handicap. They found that staff interacted more, and used more structured activities, with the more able groups.

The behaviour of the staff came under even closer scrutiny in a study by Warren and Mondy (1971) that looked at responses to the behaviours of residents with severe and profound handicap and found that staff ignored 79% of appropriate behaviour, encouraged only 18%, but responded to 29% of inappropriate behaviour. This finding has been replicated by Felce et al (Felce, Saxby, de-Kock, Repp, Ager and Blunden, 1987) in a variety of residential settings, though the smaller group homes fared better. The reasons for this were not clear.

Interactions in different environments were examined by Thomas et al (Thomas, Felce, de-Kock, Saxby and Repp, 1986), who used time sampling to compare staff-resident interactions in institutions and small homes. They used a detailed technique which coded staff behaviour for antecedents and consequences, and resident behaviours for appropriate and inappropriate engagement (e.g. leisure or aggression), social interaction (with other residents or staff), and neutral behaviours (e.g. passive). In the smaller homes they found higher levels of engagement and staff attention, and that the residents engaged in less inappropriate and more appropriate activity.

Other studies have looked at interactions outside of residential settings. Ware and Evans (1986) observed the interactions between children with profound handicap and teachers in a special care classroom, recording the initiator; mode of initiation; whether teacher initiations allowed for a response; and all responses to the initiation. They note that the behaviour rate of children with profound handicap is much lower than that seen in normal children but found that, though the majority of initiations were by the teachers, most of these did not allow for a response. They conclude that children with profound handicap are not being encouraged to participate or initiate in interaction. Houghton, Bronicki and Guess (1987) conducted similar classroom observations of opportunities to express preference given to students with mild to profound mental handicap. They found that staff responded at very low rates, and staff and students tend to use different response modalities to communicate, the staff using symbolic language, the students non-verbal behaviours. They also point out that modern approaches to educating people with profound handicap, which rely so much on the teacher's instruction, may actually discourage initiations from the student, even though developmental studies have shown that a reciprocal relationship between child

and caregiver is crucial to communication and social responsiveness (e.g. Stern, 1977).

There are a number of studies of ways of improving the rates of interaction. Cole (1986) has looked at the procedure used in some U.S. schools whereby a child with severe or profound handicap is matched with a non-handicapped peer for play sessions. Bigelow and Griffiths (1974) used time sampling to observe the decreases in maladaptive behaviour following behaviour modification and the increases in interaction which followed.

The majority of studies which have attempted to increase rates of interaction have taken a behaviour modification approach. These studies do not examine the abilities which people with profound handicap may have, or reasons for abilities being absent, but theorize that deficits may be made up by suitable training. In one of the earliest of these studies, for example, Paloutzian et al (Paloutzian, Hasazi, Striefel and Edgar, 1971) used a modelling procedure to train social responses in a group of institutionalized children with profound handicap. They claimed some success, and cited anecdotal evidence suggesting that the learning may have generalized to different settings. Using a similar approach, Cone et al (Cone, Anderson, Harris, Goff and Fox, 1978) increased social interaction and reduced self-stimulatory behaviours in five people with profound handicap using formal training, stimulus control, and rewarded generalization procedures. Mayhew, Enyart and Anderson (1978), working with institutionalized subjects with severe and profound handicap, used only reinforcement techniques and systematically ignored all behaviours except social ones, which were reinforced. This increased their occurrence. When reinforcement was stopped, social behaviour declined. They suggest that deficits in social behaviour seen in people with profound handicap may be due to a failure of environmental support. Similarly, Singh and Millichamp (1987) used verbal and physical prompts to increase independent and social play in 8 people with profound handicap. Social interaction increase markedly when social play was taught. In both cases appropriate play increased and stereotyped behaviours decreased. Behaviours remained in the repertoire of the subjects 12 months after the termination of reinforcement.

An attempt to train residential staff in the techniques of behaviour modification was made by Ivancic et al (Ivancic, Reid, Iwata, Faw and Page, 1981), who taught staff several simple behavioural methods for increasing vocalization in five people with profound handicap. They were taught to vocalize more, to encourage imitation

and to praise all resident attempts to vocalize. At first this training was confined to bathing periods, but staff behaviour generalized to other settings and appeared to be maintained, and vocalizations of the subjects increased.

Behaviour modification techniques are not the only ways to increase interaction. Horner (1980) has used an approach combining differential reinforcement to reward social behaviour with an improved physical environment enriched with toys. This resulted in increased object-directed behaviours and reduced maladaptive behaviours, though little change in adult-directed behaviours. Other techniques for improving interaction include the use of a room manager (see section 2.7). McBrien and Weightman (1980) used room management techniques with a class of 7 children with profound handicap. The room manager handed toys to the children, prompted the unengaged and rewarded the engaged, whilst other staff worked with the children individually. Using time-sampling, staff attention was monitored, and a profile of what constituted engagement for each child was devised to determine changes. It was found that the quality of attention given to the children improved, and that levels of engagement increased significantly. Porterfield, Blunden and Blewitt (1980) used a room manager to provide a stimulating environment by introducing suitable materials and giving positive attention differentially to those who were engaged. This proved more effective in increasing and maintaining engagement with people with profound handicap than prompting those who were not engaged, though Sturmey and Crisp (1982) have criticized the methodology of the study, and Petersen, Austin and Lang (1979) have claimed similar increases in social behaviour - though possibly with less handicapped subjects - by prompting.

These are the major studies of interaction in people with profound handicap. There are not many, and they have tended to adopt similar, very narrow approaches such as a concentration on the behaviour of the staff. In addition, many have used subjects with severe handicap as well as those with profound handicap, or else a size of sample that is too small to allow conclusions to be made about people with profound handicap in general. A summary of these studies is presented in Table 3.3 (over).

Authors:	Subjects:	Setting:	Type:	Topic:
Dailey et al (1974)	37 m-pmh	h	o	general & staff attitudes
Veit et al (1974)	37 s/pmh	h	o	general & context
Hermanson et al (1977)	77 pmh	h	o	general & context
Reuter et al (1980)	39 s/pmh	d	o	general & context
Harris et al (1974)	37 s/pmh	h	o	general & staff ratio
Wright et al (1974)	16 pmh?	h	o	general & behaviour of staff
Repp et al (1981)	282 s/pmh	h/d	o	general & behaviour of staff
Ware et al (1985)	9 pmh	c	o	general & behaviour of staff
Felce et al (1987)	90 s/pmh	d/g	o	general & staff responses
Thomas et al (1986)	50 s/pmh	h/d/g	o	general
Mansell et al (1984)	6 s/pmh	g	o/r	general
Rawlings (1985)	23 s/pmh	h/g	o/r	general
Close (1981)	15 s/pmh	h/g	o/r	effects of moving residence
Felce et al (1986)	6 s/pmh	h/g	o/r	effects of moving residence
Bigelow et al (1974)	21 s/pmh	h	i	reinforcement
Mayhew et al (1978)	18 pmh	h	i	reinforcement
Cone et al (1978)	5 pmh	d	i	training/reinforcement
Horner et al (1980)	5 pmh	h	i	reinforcement/enriched envir.
Ivancic et al (1981)	5 pmh	h	i	staff training/reinforcement
Peterson et al (1979)	3 s/pmh	c	i	prompting
Singh et al (1987)	8 pmh	h	i	prompting
Porterfield et al (1980)	8 pmh	d	i	room manager
McBrien et al (1980)	7 pmh	c	i	room manager

**Table 3.3 Studies of Interaction in Profound Mental Handicap**

KEY:			
Setting:	h:	Hospital.	g: Group home.
	d:	Day care unit.	c: Classroom.
Type of Study:	o:	Observational, looking at staff and subject behaviours, including interaction.	
	o/r:	Observational, comparing two or more types of residence.	
	i:	Intervention, attempting to increase interaction.	

Apart from the studies of interaction described above, studies of more detailed aspects of the communicative abilities of people with profound handicap are virtually absent in the literature. Fraser and Ozols (1983) have looked at the ways in which people with profound handicap signal distress non-verbally. Kawada (1986) looked at the effectiveness of signals used to indicate a need, finding that teachers understood 61 out of 79 students with severe or profound handicap at least once a day when they used a variety of pre-linguistic behaviours as signals. Goode and Gaddy (1976) have looked at ways in which alingual, deaf-blind people with profound handicap can signal a preference, and suggest careful observation and scaling of behaviours along a preference-dispreference dimension. Burford (1979) has looked at the rhythms of the movements of people with profound handicap and their carers during interaction, and found remarkable stability.

This, then, summarizes all the available research which has looked at interactions and communication in people with profound handicap. As can be seen, different studies have taken 'interaction' to mean different things. In some studies interaction is used to refer exclusively to the behaviour of the staff, and refers specifically to attempts to engage in interaction with handicapped residents by directing social behaviour at them. Such studies are designed mainly to assess differences in the styles of staff behaviour in different residences. Other studies have used interaction as one aspect of adaptive behaviour, counting it alongside the performance of self-help skills as 'desirable behaviour', as opposed to 'maladaptive behaviour'. Here, the use of interaction is synonymous with 'engagement'. Most studies do not define this, and it is taken generally to mean paying attention to - or responding socially to - the staff (though McBrien and Weightman, recognizing this vagueness, gave criteria for engagement for each of their subjects individually).

In most studies there is little or no detail about the characteristics of the interactions involving people with profound handicap. Typically, there is a reference to the context in which the interaction took place (e.g. a request by one of the staff), the mode (e.g. physical) and the initiator (usually the staff), but very little else. This leaves a number of unanswered questions, such as: how can we define engagement in people with profound handicap? How much eye contact is used? Is there a preference for physical contact? Do people with profound handicap use facial expressions, modulations of the voice, or gestures of the hands to convey feelings? Do they respond to emotions? Does medication affect the quality of interactions? How long can people with profound handicap interact for - minutes or seconds? These aspects have not been studied.

### **3. Some Comments on the Review of Research**

This review has summarized the extent of our knowledge about people with profound handicap, and it is fairly mixed. Generally, people with profound handicap are not considered ineducable, and important steps have been taken in attempting to teach a wide variety of skills, including communication skills, with modest degrees of success. Steps have also been taken towards recognizing that they are sensitive to their environment, and that it is important to identify the factors which contribute to a successful residence and education. There has also been a growth in our understanding of the aetiologies of profound mental handicap, attempts to provide



appropriate assessment, and an increased awareness of the problems in prescribing medication.

These advances have not been seen in all areas of profound mental handicap, however. We know more about the characteristics of learning, but we still know very little about the characteristics of behaviour - particularly the social, emotional and communicative aspects of behaviour - and about its motivation.

To go any further in tackling this problem, it is important to place this research in the wider context of what we understand about profound mental handicap as a condition. The next chapter therefore discusses ways in which profound mental handicap has been understood, what theoretical frameworks have been used, and suggests a new direction for future research.

## CHAPTER 4. A FRAMEWORK FOR CONSIDERING PROFOUND MENTAL HANDICAP

### 1. What Frameworks are Used with People with Profound Handicap?

Most studies of people with profound handicap have been content to focus in on a narrow area and refer only to research which relates to that one area, rather than propose any general theoretical base for understanding behaviour. Thus, the research is not placed within a wider framework, and the theoretical approach to the nature of profound mental handicap beyond the limited context of the study is given little or no attention.

Before the late 1950's, the approach underlying most studies of people with profound handicap could easily be discerned. They were essentially descriptive, comparative, predictive and nativist in sentiment (Berkson and Landesman-Dwyer, 1977). Rooted firmly in medical tradition, they generally sought only to list the 'symptoms' of profound mental handicap. More recently, the study of profound mental handicap has found more extensive roots in neurology, human ethology, learning theory, and developmental theory<sup>1</sup>.

Studies based on learning theory, which make up by far the greatest number, have, in fact, no theory of profound mental handicap and no theory of how to apply 'learning theory' to people with profound handicap. Learning theory is not a theory of mental handicap, or of intelligence, it is a theory of the processes of learning, explicitly concerned with techniques that enable a change in the frequency of a specified behaviour. Learning theory treats subjects with profound handicap as it would any other, and herein, I believe, lies the cause of most of the methodological problems in behaviour modification studies outlined in the previous chapter: people with profound handicap are not like any other subjects. There are characteristics of learning in people with profound handicap (a fundamental lack of generalization, increased forgetting etc.) which seem peculiar to them as a group, and which therefore have to be taken into account. In other words, if we use learning theory, we must also

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<sup>1</sup>Actually, the first use of both an ethological approach and a developmental approach can be dated back over fifty years to the same researchers, Aldrich and Doll (1931 a and b), but these studies are very much exceptions for their time.

use a theory of profound mental handicap, or a theory of learning *and the motivation for learning* in people with profound handicap.

The human ethological approach (as advocated by Cleland, 1979) comes closer to providing a rationale for the ways in which people with profound handicap actually behave. This uses techniques of observation developed in studies of animal behaviour and tends to attempt to understand behaviour in terms of its function, pre-requisites, influencing factors and outcome, and with reference to knowledge obtained from studies of similar non-human behaviours. The number of such studies is small, but the approach can be informative. These studies have provided fresh insights into several, isolated aspects of behaviour such as tool use (Cleland, Rago and Mukherjee, 1978). The wider applications of the approach are limited, however, by the fundamental differences between animal and human behaviour, which are no less apparent when the human has a profound handicap. Most notable among these differences are the emotions by which human communication is regulated.

Some studies have been based on neurology (e.g. Dobbing and Balazs, 1984), and these are perhaps the inheritors of the medical tradition. Progress has been made in identifying aetiologies and methods of prevention, but there has been no great advance in understanding the behaviour of people with profound handicap from this source. No direct link is apparent between brain pathology (which tends to be diffuse) and behaviour. In addition, once the handicapping condition has occurred, there can be no 'cure' for the person with profound mental handicap, and knowledge of the neural cause in each individual case may add nothing to an understanding of how we can best care for that individual or explain his behaviour, or that of people with profound handicap in general.

These approaches do not themselves provide a wider framework for considering the nature of profound mental handicap, but an underlying thread of interpretation in them all considers people with profound handicap as if they were the most severe case of an incomplete development. A developmental framework is implicit in the classification and assessment of profound mental handicap and traditionally forms the basis for a conceptualisation of the condition used by all those who work with or study them. Although only a few studies have actually made developmental status the subject of research, a developmental approach offers a framework on which to compare their behaviours and abilities with a normal population (in the case of people

with profound handicap, with infants and young children), and perhaps thereby finding a way to understand them better.

## **2. A Developmental Framework**

Development in people with profound handicap is, of course, extremely limited when compared with normal development. In effect, people with profound handicap are functioning at a level which approximates that of infants or young children, with, of course, important differences. It is natural, therefore, that normal early development has been used as a framework with which to measure the level of functioning of people with profound handicap. This can most readily be seen in assessment procedures and the same concept is inherent in all classifications which rely on a comparison of mental ages. Although some researchers (e.g. Switzky, Rotatori, Miller, and Freagon, 1979) have warned that normative development cannot be assumed in people with profound handicap and that studies have to recognize this, a developmental framework is generally chosen as a starting point in examining the abilities of people with profound handicap and the changes that take place over time, and belief in a residual developmental process has a most important influence on most attempts at education and intervention.

Studies which have investigated the development of people with profound handicap have overwhelmingly opted for a Piagetian framework (e.g. Woodward, 1959, 1970; Silverstein, Brownlee, Hubbell and McLain, 1975, 1981; Kahn, 1979; Webb and Koller, 1979; Lobato, Barrera and Feldman, 1981; Wohlheuter and Sindberg, 1985; MacPherson and Butterworth, 1988). Piaget's theory of development is summarized in appendix II. The main tenets are that the child is actively engaged in constructing and understanding the world from birth, and in the first 15 years normally progresses through 4 stages of development. The first (Sensorimotor: birth to 2 years) has six sub stages and covers development from reflexive behaviour to the earliest stages of language.

Development is considered to occur across several functional 'domains' simultaneously, with stages marking important changes in mental structures. In the sensorimotor period there are six domains of development: the realization that objects (and people) have a separate, permanent existence; the development of spatial understanding; means-ends behaviour; causality; and imitation.

The developmental process is described in terms of cognitive 'schemes', which refer to the 'tactics' or behaviour patterns that the infant uses in order to understand the world (e.g. mouthing, holding, shaking, dropping an object), which are modified through experience and typify different stages. The sequence through which the stages are passed is considered invariant (for example, stage I has to be passed before progressing to stage II). Attainment of the various stages and sub stages is deduced from behaviour on clinical developmental tests which demonstrate the mental processes being used.

An impetus for a developmental approach has come from the delay-difference controversy which has raged for some years amongst researchers into mental handicap. Briefly, the delay or developmental lag theory (Zigler, 1969) holds that development in mental handicap is only quantitatively different from normal development - i.e. it is the same but delayed - and that the same developmental sequence is passed through by a handicapped child but at a slower rate, sometimes to the point where later stages are never completed. The difference or defect theory (e.g. Ellis, 1963) states that there is a qualitative difference in development - that development in people with a mental handicap is completely different, with no orderly progression through the same sequence of stages as is seen in normal development.

These two theories obviously have different implications for an understanding of mental handicap and for approaches to intervention, and their rival claims have generated a great deal of research. Both schools of research have tended to use a Piagetian framework and some have looked at people with profound handicap (e.g. Silverstein, Pearson, Keller and McLain, 1982). In the main, the findings have tended to support the developmental delay theory, indicating a slower but orderly progression through Piaget's stages. In fact, there is an implicit assumption of developmental delay when an adult with a mental handicap is described in terms of mental age, which implies that comparison may be made with a child of the same mental age, even though when this is done those with a mental handicap invariably produce a worse performance.

Results are not conclusive, however, and they are particularly dubious with people with profound handicap. Rogers (1977), for example, looked at the behaviour of 40 young children with profound handicap across several domains of development and found that several domains (such as object permanence, imitation and knowledge of causality) appeared to be completely independent of each other, there being no



orderly developmental progression as would be expected from Piaget's theory (though it can be argued that such a lack of synchrony has also been found in the normal population).

In practice, much depends upon the level of investigation. In language acquisition, for example, a child with mild mental handicap may achieve an overall language score similar to that of a younger normal child, and it may be concluded that language acquisition is merely delayed. When the individual components of the language system are examined, however, it may be that the stages of development are very different. Thus a handicapped child of 7 may have a 5-year-old's lexicon and a 3-year-old's syntax and be, therefore, not functionally equivalent to any normal child. In addition, the balance between individual aspects and the overall picture may vary within different areas of development at different times. It is also worth remembering that we do not yet know enough about individual differences in development in the normal population to decide when a deviation becomes a difference.

A much stronger criticism, which applies to both theories, questions the validity of applying either of them to individuals who have the multiple aetiologies, additional handicaps, and evidence of gross brain damage, all typical of people with profound handicap. Surely it is ludicrous not to admit that development is likely to be both different from normal and delayed in people with profound handicap? In fact, Zigler himself never meant the delay theory to be applied to the more handicapped groups.

In spite of these problems, many studies have looked for similarities between people with profound handicap and infants and have attempted to place people with profound handicap on a scale of normal development. Since their intellectual functioning is assumed to be within Piaget's Sensorimotor stage, there being little or no, 'representational functioning', research has looked at the domains of development in this period for signs of what steps and sub-stages people with profound handicap are capable of attaining (Lobato et al, 1981), whether they are capable of further cognitive development (Silverstein, Pearson, Colbert, Cordeiro, Marwin and Nakaji, 1982), and how well any such development predicts future learning skills (Kahn, 1983).

Although there is a predictably wide individual variation, studies show that the structure of sensorimotor intelligence in profound mental handicap is different from that of other infants, and that what developmental progress there is may not be strictly according to Piaget's order of stages (Macpherson, 1984). Generally, and bearing in mind that there is still uncertainty about how domains develop and the amount of individual differences in the normal population, these studies might best be seen as descriptive rather than comparative.

These studies have found that the cognitive stage of people with profound handicap is related to the development of adaptive skills, in particular language skills. They perform poorly on gestural and vocal imitation tasks, and on object permanence. Development in these areas predicts progress in language, social behaviour, and to some degree independence skills (Kahn, 1983), though after five years Silverstein et al (1982) found only small gains on cognitive tasks, and no change in object permanence scores. An intervention program is the ultimate aim of many researchers. Butterworth and MacPherson (1985) have attempted training in imitation and object permanence with some success, and Webb and Koller (1979) have attempted sensorimotor training using sensory stimulation, producing gains in awareness, gross motor and adaptive skills but none in imitation or fine-motor control. Thus, intervention, though it has not yet been completely successful, has produced some promising results.

A serious drawback with such studies, however, is that, being based on Piagetian theory, they are constrained by it in the aspects of development which are studied: Piaget's theory is a cognitive theory of development that is not concerned directly with interpersonal and emotional developments. The latter are precisely the aspects in which many exciting advances are now being made in developmental psychology, and they may have great implications for the research and theory of profound mental handicap.

### **3. Emotional and Communicative Development in Infants and its Relevance to people with profound handicap**

Although overshadowed until recently in theories of development by studies emphasizing cognitive development which were rooted firmly in the Piagetian tradition, an area of developmental psychology in which particular advances have been made in the last decade is that concerning the emotional and communicative functions of infants (e.g. Bullowa, 1979; Stern, 1979, 1985; Trevarthen, 1983, 1985, 1986; Schaffer, 1971, 1977). The major findings in this area are summarized in a table in Appendix III, which covers the first two years of human development. This research has important implications for an understanding of people with profound handicap.

Gradually, our appreciation of what infants can do and what they can experience has changed as research has shown the extraordinary abilities of infants to take an active role from birth in engaging with the social environment. This centres around the ability of the infant to form a relationship or 'attachment' with the mother (Bowlby, 1969), and, within this relationship, to participate in a rich system of communication from the earliest times. Newborn infants are biologically predisposed to enter into and regulate social exchanges and interaction, enabling the sharing of mental states (Trevarthen, Murray and Hubley, 1981).

At birth an infant can see over a short distance and usually shows signs of discriminatory awareness of events - particularly social events. By studying gaze preference, it has been shown that neonates are attracted to patterns that resemble the human face (Fantz, 1963; Haith, Bergman and More, 1977) before and after they acquire, at two months, the ability to scan the internal features of the face (Salapatek, 1975), and that the closer this pattern is to a real face, the more attractive it is (Maurer, 1985). The attraction is particularly strong for the face of the mother (Carpenter, 1974). In fact, infants can also identify their mother from her odour, her voice, and the rhythms of her movements (Field and Fox, 1985).

Infants also show the capacity to discriminate and imitate the facial movements of others (Meltzoff and Moore, 1979, Kugiumatzakis, 1985), a striking ability which requires that they have a representation of their own and others faces and the ability to match them internally, even though they cannot actually see their own face. The implication is that an infant does not see others as a set of stimuli to respond to, but as a person who is a potential partner in communication. This is confirmed by neonatal

responses to the patterning of facial movements to produce emotion-like signals such as happiness or sadness: Infants respond to changes in a mother's expression with the appropriate interpersonal expressions conveying the appropriate feelings (Murray and Trevarthen, 1985).

The emotions are an important part of the infant's life from the earliest times, and a baby may demonstrate the full spectrum of emotions at birth. Although the neuro-motor system is immature at first, the facial expressive system develops before 30 weeks gestation and a newborn infant can generate facial expressions of emotion which compare closely to those of adults (Oster, 1978). Newborns are capable of organized facial expression defining distinct communicative states, and they respond to stimuli given by an affectionate mother. In particular, neonatal smiles, while frequently unsolicited and fragmentary, are responsive to affectionate maternal communication and after 3 weeks become stronger, more regular, and coordinated with cooing (Wolff, 1969). At two months, an infant's facial expression during interactions with the mother give evidence of an innate representation of her as a partner in communication, and for an emotional system that evaluates her expressions and regulates their interpersonal contact. This emotional communication is multimodal, and as infants gain in perceptuo-motor and cognitive powers, they both express and respond to simultaneous signals of affect in multiple channels of voice, gesture and postural change (Trevarthen, 1985).

The infant, then, appears to possess and express human emotions, having an awareness of how others communicate and a capacity to respond to and influence them. This innate underlying psychological capacity makes possible soon after birth a period of rich communication between mother and baby which has been called 'Primary Intersubjectivity' (Trevarthen, 1979). This period, from about 5 or 6 weeks to around the 4th month, is typified by the infant striving for direct face-to-face communication with the mother, consistently seeking eye contact and attending to her voice. There is a wealth of communicative behaviour from both partners and the interaction takes a conversation-like form, with both partners sensitive to the responses of the other. This is regulated by a turn-taking pattern, governed by a mutual awareness (mirroring) of emotional and expressive states conveyed by movements with controlled temporal organization and form (Trevarthen et al, 1981).

This interpersonal communication requires precise temporal sequencing and co-ordination of the action patterns of the participants: analysis shows that mother and

infant are coordinated with timing precise to a fraction of a second (Beebe, Jaffe, Feldstein, Mays and Alson, 1985). Such abilities appear to be largely innate. The tempo and organization of the spontaneous movements and prespeech vocalizations of the infant have been shown to have an intricate temporal relationship with those of the mother: Condon and Sander (1974), for example, have found that the movements of a neonate can become synchronized with the speech of adults nearby twenty minutes after birth.

Similarly, the mother establishes a tempo for her own movements to best maintain her infant's attention and involvement, keeping a constant visual check on the baby's movements. At the same time, adults tend to speak to infants in 'motherese', a linguistically simplified form of speech characterized by high pitch and exaggerated intonation, which infants have been shown to prefer over other forms of speech (Fernald, 1985) and which appears to have a similar tempo and form to spontaneous infantile movements (Trevvarthen and Sylvester-Bradley, 1978). It also seems that the prosodic features of motherese (pitch, frequency range, increased pause duration etc.), which is the most distinctive feature of this type of speech, is universal to mankind, having been found in English, German and Mandarin Chinese speaking mothers (Grieser and Kuhl, 1988). Adults seem to have a basic vocabulary of actions and vocalizations appropriate to interacting with infants and an ability to use timings which produce the maximum effect, and this appears to be largely intuitive.

The end result is a biologically based dance-like interaction, with both partners unconsciously taking an active and sensitive role. This mutual control is seen clearly in experiments which have deliberately perturbed the interaction by having the mother give an inappropriate response. The interaction breaks down and the infant is distressed, demonstrating an organized sensitivity to human expression (Murray and Trevvarthen, 1985).

During the 4th month interpersonal contact diminishes as the baby turns from the mother to explore nearby events and objects. Nevertheless, this exploration is securely founded on the support of the mother, who is increasingly drawn into the infants growing interest in objects. Communication develops through game playing, usually musical and featuring singing and physical play (rhythmic body movement), in which the baby becomes increasingly interested and in which temporal patterning still plays an important part. The mother continues to be sensitive to her baby's preferences (Trevvarthen, 1982).



This research provides an insight into the changing regulatory function of the brain in development. Development can be seen in terms of unfolding brain states and the brain can be seen as controlling the interaction between self and the environment. Emotions are crucial in this: they are the motivation for active development. Throughout development, the caregiver - and the relationship which exists with the caregiver - has a vital role, regulated by the communication that occurs from the earliest times.

To summarize, infants appear to be born with an intact emotional system and the ability to join in a biologically 'pre-wired' primitive non-verbal communication with others, whilst adults are predisposed to respond in a way sensitive to the infants needs.

Some kind of developmental framework is undoubtedly useful for understanding people with profound handicap, but as can be seen from this brief review, if a Piagetian framework is adopted many very important behaviours will be left out. What is worse, these very behaviours may represent the most important features of the behaviour of people with profound handicap. The inadequacy of a purely Piagetian approach are shown clearly in Table 4.1, which follows. This illustrates Piagetian development using Piagetian tasks and items taken from the Piagetian-based assessments of Uzgiris and Hunt (1979) and Dunst (1982). This is compared with a summary of interpersonal developments (communicative and emotional) occurring at the same time, taken from research including that of Bullowa (1979); Stern (1979, 1985); Trevarthen (1979, 1982, 1983, 1985, 1986); Trevarthen, Murray and Hubley (1981); Field and Fox (1985); and Schaffer (1971, 1977).

The top half of the table gives examples of behaviour typical of each of the Piagetian substages of the sensorimotor stage, together with appropriate ages for its appearance in normal development. The behaviours are presented in terms of six Piagetian 'domains' or areas of development (e.g. 'visual pursuit and permanence of objects'), which is how the theory, and the assessments, are structured.

The bottom half of the table uses research into the development of infant communication to identify communicative behaviours appropriate for the age ranges of each of Piaget's substages. This enables age related behaviours taken from Piagetian theory to be compared with behaviours obtained from studies of communicative developments that occur at similar ages.

A comparison clearly reveals inconsistencies between the two approaches which seriously restrict the usefulness of a Piagetian approach. In Piaget's theory, for example, imitation of simple adult gesture does not appear until Stage III (4-8 months), whereas it has been demonstrated that infants may attempt to imitate a mother's tongue protrusion at the age of twenty minutes (Meltzoff and Moore, 1979, Kugiumatzakis, 1985). As mentioned before, this behaviour involves the representation of the topographical resemblance between the infant's body and the model person: basically, the infant has an image of the other person and is aware of the relationship with his own body. Traditional Piagetian theory cannot explain this extraordinary behaviour.

There are, in fact, many developments in communication which are of crucial importance but which are not covered - or are covered in little detail - in a Piagetian approach. The period from 1 to 4 months ('Primary Intersubjectivity') is one of an astonishing richness in communication which all indications suggest is vital for subsequent development. This is not reflected in the Piagetian tasks for assessing behaviour appropriate to this age.

When the Piagetian approach is considered with reference to people with profound handicap, the shortcomings are even more obvious. As has been mentioned, sequential development of cognitive abilities is questionable in people with profound handicap, and development across domains may be unequal. More importantly, by emphasizing abstract stages in cognitive development at the cost of communicative and motivational development, it may be missing the bulk of the abilities which people with profound handicap possess.

	0-1 month: I REFLEXES	1-4 months: II PRIMARY CIRCULAR REACTIONS
VISUAL PURSUIT & PERMANENCE OF OBJECTS	<i>reflex behaviours and radical egocentrism</i> * Jerky tracking of objects. * Fixates on object 8-10 inches above eyes.	* Visual pursuit of object through arc of 180 deg. (n.b. size of arc, characteristics and speed of object and head/eye movements are all involved in tracking).
DEVELOPMENT OF MEANS FOR OBTAINING EVENTS	* Activity level increases or decreases on seeing a visually presented object.	* Engages in hand watching.
DEVELOPMENT OF GESTURAL IMITATION	* Attends to gestures performed by adult.	* Performs consistent acts in response to simple familiar gestures (e.g. shakes rattle, squeezes toy, bangs spoon on table) or complex gestures composed of familiar gestures (e.g. pat-a-cake).
DEVELOPMENT OF VOCAL IMITATION	* Responds to voice .	* Vocalizations other than crying. * Shows positive response to familiar cooing and babbling sounds; at 3m, will vocalize in response to cooing sounds.
OPERATIONAL CAUSALITY	* Vocalizes and/or smiles in response to adult talking.	* Generalized body/limb movements observed to produce contingency. (* Engages in hand watching).
SPATIAL DEVELOPMENT	* Searches for sound with eyes.	* Localizes source of sound * Alternates gaze between two objects, slowly at 2m; rapidly by 3m
DEVELOPMENT OF SCHEMES FOR RELATING TO OBJECTS	* Palmar grasp; grasps examiners finger . * Reflex sucking .	* Retains object placed in hand for 10-15 secs * Mouths objects placed in hand * Visually inspects objects held in hands.
COMMUNIC-- ATION	* Differentiates sounds. * Produces discomfort sounds: cries; fusses. * Periods of alert inactivity; sleep cycle. * Self synchrony present in movements. * Entrainment with adults speech/movement * Periodicity in movements compatible with those of adults. * Turntaking pattern in non-nutritive sucking behaviour. * Consistent preferences in perception (visual & auditory) for human features, especially the mother. * Spectrum of human emotions at birth * Able to recognize mother from sight, odour sound of voice, rhythm of movements. * Imitation of simple facial gesture from birth. * Amodal sensory transfer	* Extends and turns neck when prone. * Produces comfort sounds: cooing; laughs. * Sustained periods of eye contact. * Communicative expressions used: cooing , prespeech (simple articulation), smiling and facial expressions. * Speech-like pattern of proto-conversational communicative exchanges between infant & mother (turntaking/coaction) is similar to that in adult speech. * Mutual regulation of exchanges: infant is active partner in dyad. * Regulation based upon shared rhythm of movement * Emotional expression through face/voice / lip and tongue movements/hand movements/posture/gesture * Fear of strangers.

**Table 4.1 Piagetian and Interpersonal Aspects of Development**

4-8 months: III SECONDARY CIRCULAR REACTIONS	8-12 months: IV COORDIN. OF SECONDARY SCHEMES
<i>contingency awareness</i> * Smooth fixation and tracking of objects. * Visual search for vanished object. * Retrieval of partially hidden object .	<i>object permanence and object concept established</i> * Search for and retrieval of hidden object.
* Arm movements repeated systematically to keep a toy active. * Efficient visually directed reaching . * Intentional seeking of objects .	* Pulls a support (e.g. a piece of cloth) on which desired object is standing; removes obstruction. * Uses some form of locomotion to get object * Drops object from hand to hold another object
* Some simple familiar gestures imitated. * Attempts to imitate complex gestures made up of simple schemes by gradual approximation.  * Imitates cooing sounds. * Vocalizes in response to babbling sounds. * Vocalizes in response to familiar words .	* Complex gestures made up of familiar schemes are imitated. * Unfamiliar gestures that are visible imitated.  * Imitates babbling sounds and familiar words. * Vocalizes in response to unfamiliar sound patterns (e.g. room-room, ding-dong).
* Consistent discrete movements produce contingency. * Arm movements repeated to keep a toy active. * Uses procedure as causal action in familiar game or in response to behaviour created by agent.	* Touches adults hand as a causal action - behaviour. * Touches adults hand in response to adult activating mechanical toy.
* Secures visually presented objects . * Follows trajectory of objects falling within view	* Follows trajectory of object falling out of view. * Rotates objects to view functional side. * Drops objects in container; plays xylophone. * Egocentric in spatial tasks.
* Voluntary grasp of object. * Coordination of sight and grasp to manipulate. * Uses simple motor schemes towards objects: banging, and hitting, later: shaking, dropping, rotating.	* Socially instigated actions to self and/or others. * Uses combinations of previously learned actions (complex motor schemes): tearing, sliding, swinging, observing dropping.
* Keeps head above horizontal for long periods. * Lip & tongue control increases: babbling after 5m. * Reduced levels of face to face contact. * More interest towards environment than mother. * Play changes: more vigorous, more socio-dramatic role playing; appearance of stubbornness, rivalry, deceit, and temper tantrums (increased autonomy of purpose). * Much musical/rhythmic play (e.g. nursery rhymes chants, games) based on beat common to all cultures. * Mother used as source of security from which to explore world. * Early situational understanding and phrase  * Identifies words in phrases in familiar settings	* Sits well; crawls; pulls self to sitting position. * Canonical Babbling associated with object manip * Development of 'cooperative awareness': a willingness to participate in joint tasks and comply with mothers instructions in object use. * Self-conscious behaviour before mirror; 'showing off' (performances) in front of others: awareness of conventional acts/artifact/tool use. * Pride in knowledge of conventions. * Assimilates conventional gestures into expressive repertoire: conveys wishes, denials etc. in accepted way. * Aware that others possess intentions/feelings. * Sensitive to mothers feelings; shared humour. recognition, with some appropriate responses.  * Emotional referencing of objects ('bad knife') * Attempts to imitate specific words/gestures. * Heightened fear of strangers.

12-18 months: V TERTIARY CIRCULAR REACTIONS	18-24 months: VI INTERNALISATION OF SCHEMES
<i>means-ends behaviours</i> * Retrieval of object observed hidden under one of two, later three screens - hidden alternately.	<i>appearance of symbolic thought</i> * Retrieval of object secretly hidden beneath one, later two of three screens - (alternately). * Retrieval of object secretly, successively hidden with 3 screens - under last screen, searched first.
* Pulling only attached string horiz. or vertically or using stick to gain desired object. * Opening/emptying matchbox; fill with necklace * No attempts to stack solid ring after one attempt.	* Foresight shown in placing chain in matchbox. * Foresight by no attempt to stack solid ring. * Uses stick to push toy from transparent tube. * Uses stick to push toy from opaque tube.
* Attempts to imitate familiar invisible gestures (e.g. putting out tongue, patting own head), with/without objects, through gradual approximation.  * Imitates unfamiliar sound patterns and novel words by gradual approximation. * Imitates unfamiliar sound patterns at 17m. * Imitates one novel word at 18m.	* Can successfully imitate three invisible gestures with and without objects.  * Imitates two novel words at 20m. * Imitates at least four novel words by 23m.
* Pushes/pulls adults hand, later uses gestural/ vocal behaviours to have a behaviour repeated. * Gives object to adult to be activated. * Repeats behaviour/shows off to hold attention.	* Searches for causal mechanism needed to activate wind up toy with, later without, demonstration from adult.
* Stacks rings; builds tower from two blocks. * Allows object to move down incline. * Makes simple detour to gain desired object.	* Makes complex detour from cul-de-sac to gain desired object. * Indicates the absence of familiar persons.
* Objects shown to others; instigates social action * Social actions with respect to objects appear: pretending to drink from cup, building structure with blocks, dressing a doll, driving a toy car).	* Deferred imitation of others actions (e.g. wipes siblings nose, wipes dolls nose later). * Objects spontaneously named. * Symbolic play - object represents other object.
* Object manipulated in different ways for novelty * Understanding of speech develops. * Words used to signal awareness of shared reality * Utterances and gestures coordinated with attention of mother (protolanguage). * Beginning to understand object labels; selects a few objects in response to naming; uses a few situational words (e.g. 'bye-bye', 'ta', 'no'). * Babbling more complex/interactive. * Uses pre/proto words. * Most utterances purposeful: directs attention etc. * Understands specific words/commands in context * Emotional referencing of objects (e.g. 'bad knife').	* Cruises and walks with one hand held. * Turns to mother to explain unfamiliar objects. * Can obey or ignore mothers instructions. * Fluent vocalizations and gestures indicate excitement. * Learns meanings of domestic rituals and social conventions; acts out fragments of ritual (e.g. eating, drinking, using tools). (Process begins in first year). * Mastery of social/cultural skills dependant on affectionate support. * Symbolic understanding develops ( words understood to have a meaning beyond the limits of time and space. * First two word sentences. * Achievement of true verbal labels and language



Clearly, any account of infant development must take into account the development of emotion and communication, but what relevance has this for the study of people with profound handicap? The answer lies in the behaviour of people with profound handicap when they are observed in natural environments with a responsive carer. In these conditions, they demonstrate capacities for communication which are remarkably similar to many of those outlined in table 4.1. They will, for example, use facial expression, vocalization, and touching behaviours to communicate emotional states with their carers.

The comparison is even more striking when the carer's behaviour towards people with profound handicap is considered. Carers will typically use a repertoire of behaviours that includes: patting; stroking; kissing; rocking; bouncing; cuddling; teasing; tickling; singing and rhythmic play - often physical and often involving precisely timed body movements. They observe the reactions of their partner and change their own behaviours accordingly. They will also use motherese when they speak during engagements. These behaviours are very common amongst carers. They are extraordinarily similar to those of mothers when interacting with their infants, but are used by even those carers who have no experience of children. Carers using these behaviours can be found all over the country, perhaps all over the world, yet mostly they have never been taught these skills during their training, or even had them recognized as a valid technique of care. The implication is that carers have developed these behaviours because they are successful with people with profound handicap. They have recognized (perhaps unconsciously) that the communicative and emotional needs and capacities of people with profound handicap are so similar to those of infants that similar techniques of providing them are effective.

For their part, people with profound handicap frequently show signs of achieving at least some level of communication in response to this: they may pay attention to the carer, smile or laugh in response to an action, reach out to touch the carer, or even attempt to request that an action be repeated. Unlike infants, however, they rarely show a sustained, active striving for direct contact. Periods of avoidance or unresponsiveness seem to be much more frequent. It is also likely that they will not have passed through the primary intersubjectivity stage of intimate affective engagements.

At first sight, interactions with people with profound handicap appear to have little in common with the rich variety of coordinated patterns of behaviour which

characterize mother-infant communication - eye contact, for example, is usually inconsistent or absent - but there are many similarities which have already been recognized by carers, and which could provide a valuable source of information for research.

The most important issue raised by such a comparison is the degree to which the interpersonal abilities observed in infants are present - but perhaps dormant - in people with profound handicap. As was clear in the review of infant research earlier in this chapter, there is a growing realization that many of the emotional and communicative behaviours seen in infants have an ante-natal development. The infant appears to be born with an innate preference for engagement, facilities for discriminating and being attracted by human faces (especially the mother), the capacity to express and decipher emotions, and the ability to enter into communicative exchanges of precise timing. How much of this is intact in the brain of people with profound handicap and how much these abilities can be facilitated by appropriate adaptation of the 'human environment' is a vital question.

Generally, in the day-to-day behaviour of people with profound handicap there are few examples of behaviour which suggest the involvement of the cortex. Though there are some, such as spontaneous learning and the recognition of people, it is reasonable to assume that the bulk of the behaviour of people with profound handicap has a subcortical basis. The capacities of infants outlined earlier also appear to be based in subcortical structures and, though these areas may also have suffered damage in people with profound handicap, if they are at a low level in the brain it is possible that they are less vulnerable to pathology.

Evidence now suggests that many of these capacities are indeed controlled by structures located at a very basic level in the nervous system, and in many cases similar capacities have been observed in other species. The emotional system and control of facial expression, though there is normally some cortical involvement in humans, is essentially subcortical, controlled by the reticular activating system in the brain stem, the hypothalamus, and the limbic system (paleocortex and amygdala). Rhesus monkeys appear to be able to communicate affection from birth, fear from six weeks, and aggression from six months (Buck, 1985).

The control of interpersonal timing also appears to be subcortical, and is particularly robust. A longitudinal study of Down's Syndrome infants has shown that

they are able to coordinate the temporal patterning of their vocal behaviour with the mother (and vice-versa) as well as normal infants (Jasnow, Crown, Feldstein, Taylor, Beebe and Jaffe, 1988). This coordination parallels temporal matching now found in a number of different species along the phylogenetic scale, including temporal filtering neurons found in crickets (Schildberger, 1984), similar neurons in the inferior colliculus of the rat (Rees and Moller, 1983), and a region on the x chromosome of the fly *drosophila* which is responsible for the temporal pattern of a mating song (Zerhing, Reddy, Konopka, Kyriacou, Rosbash and Hall, 1984).

Similarly, it seems as if the earliest stages in the development of language are pre-wired and controlled by regions outside of the cortex. Ploog (1979) reports that the squirrel monkey develops several distinct vocalizations (similar to the vocalizations made by many of people with profound handicap) which do not appear to be learnt and are not modified by learning. These vocalizations are regulated in the brainstem, which performs a similar function - the coordination of movements of the vocal apparatus and integration of sounds into species-specific gestures - in many species, including man.

A basis for language development is similarly genetically predetermined in infants. For the first few weeks of life vocalizations are controlled by the pontomesencephalic region of the brain. When babbling (the combination of a variety of sounds) begins at 8 weeks, control is likely to be largely subcortical, since only subcortical regions of the brain are myelinated, and more mature, at this time (Ploog, 1979). These developments are pre-wired and universal, with similar changes occurring at similar times in all infants (Lenneberg, 1967). In fact, in the first year the phonation of infants is very similar to that of primates, the main difference between our species - the position of the larynx and the emergence of the cortical larynx and facial area controlling vocal signalling - not occurring until the second year. Even during this first year, however, finely differentiated expressions of emotional states through a variety of vocalizations are possible (with the emotional input coming from the limbic cingulate area), as has been well documented in infant studies.

Emotions, interpersonal timing and early language development may thus have their origin in subcortical structures at a very basic level in the brain, and many of the abilities shown by infants are similar in some form to those present in other species, particularly the higher primates. It therefore seems reasonable to expect that such subcortical regions and the abilities they make possible are present in a fairly intact

condition in people with profound handicap. Anecdotal evidence of behaviour (e.g. use of facial expression) suggests that at least some of them are, and there is the possibility that there are many more remaining to be adequately described.

There are two points to be made concerning the possibility that capacities based upon subcortical structures are present in people with profound handicap. First, the nature of behaviour controlled by subcortical regions of the brain is essentially unconscious, and it may be that behaviours of people with profound handicap to which we attribute intentionality - such as smiling - are actually reflexive and without interpersonal meaning. This can only be resolved by examining behaviour in terms of context, and by looking for evidence of the involvement of coordination and learning, and responses to environmental stimuli.

The second point is more optimistic. It is to recognize the very real possibility that some of these capacities exist in people with profound handicap, and that they may be utilised in improving the quality of care. People with profound handicap may be viewed as having the capacity for the basic communication skills used by infants, but whilst in normal development these are superseded by the rapid development of language, in people with profound handicap there is a problem in brain development which prevents this second stage of communication from occurring. Other problems are also indicated by the differences in the quality of the interactions between people with profound handicap and their carers compared to those between infants and their mothers. This suggests that even the surviving basic communicative skills may be damaged so that they need a sympathetic environment to develop to their full extent.

This last suggestion has had practical application in Movement Therapy (Burford, 1986), and the 'Moving in Sympathy' project now in progress in the Psychology Department at the University of Edinburgh. Movement Therapy is, in part, an attempt to build upon what many long term caregivers of people with profound handicap have grown to realize: that a person with profound handicap, though s/he possesses no language skills, is nevertheless capable of communication in her/his own terms (with an intrinsic regulation). Movement therapists and successful caregivers modify the level of their own attempts at (non-verbal) communication to meet and complement the expressions and responses of the person with profound handicap, in much the same way as an affectionate mother communicates with her young infant. They also, like mothers of infants, assume that people with profound

handicap are capable of emotional responses, noting the presence of moods, laughter, emotional expression and the ability to form relationships with caregivers.

Although people with profound handicap are, indeed, extensively handicapped, the observations informed by this approach indicate that they possess often ignored, but potentially important, abilities that are functionally equivalent to those seen in young infants. They further indicate that these abilities can be developed and built upon to significantly improve the quality of life of the individual, in some cases resulting in lasting positive changes in behaviour.

The implications of this are only just being appreciated. So far, the connection between the interpersonal behaviour of infants and people with profound handicap has been made by very few people, and it has received virtually no attention in the literature, apart from Bronwen Burford's work cited above. One exciting development, however, is in the application of these ideas to education. Nind and Hewitt (1988) believe that the interpersonal abilities of children with profound handicap are central to any understanding of behaviour, and that any desirable changes in behaviour is most effectively accomplished through these channels. They therefore argue that an approach based upon interaction should make up the major part of an educational curriculum for children with profound handicap.

In summary, infant studies suggest that sub-cortical structures governing emotions and communicative skills may be relatively intact in the brains of people with profound handicap. The extent of this retention of functions is unknown, but in the right circumstances people with profound handicap demonstrate the potential to sense other individuals as individuals rather than objects, have an ability to form relationships with caregivers, and show signs of a functioning emotional system. They are able to communicate on a very basic non-verbal level with the caregiver, within limitations imposed by environmental and physical constraints on their awareness and action, and the level of responsiveness and sensitivity in the partner. There are striking similarities between the communication of people with profound handicap and infants, and between the behaviours of carers of people with profound handicap and mothers.



#### **4. An Alternative Approach to Profound Mental Handicap**

Perhaps the main point of this thesis is that it is vital to study the nature and abilities of people with profound handicap, of which the emotional and communicative may be the most important, in order to develop appropriate methods of care. Thus, I believe that as well as noting the failure of people with profound handicap to learn spoken or signed language skills and embarking on extremely long training programmes to teach the rudiments of such skills step by step, it is beneficial to study and strengthen the communicative abilities that such individuals already possess. These abilities can be considered not just as precursors to language, but as useful for interpersonal engagement in their own right.

Modern research on profound mental handicap has concentrated on changing rather than explaining behaviour. It has been limited in its theoretical approach, taking enough of a developmental theory to describe the stage of development, but not enough to attempt to place behaviour within a wider theoretical framework. More emphasis needs to be placed on understanding and appreciating all of the behaviours which are seen in people with profound handicap, rather than one isolated behaviour which is deemed desirable in a training programme. There is no doubt that behaviour programmes may have the potential to improve the quality of life of people with profound handicap, but an over-emphasis on them can obscure other equally important, spontaneously motivated and naturally stimulated aspects of behaviour.

It is clear that people with profound handicap possess a range of abilities which have not been produced by training: they are capable, for example, of communicative behaviour, they form relationships with other people, they have emotions, and they can demonstrate isolated but striking feats of memory. Interestingly, these natural abilities appear to be quite different from behaviour which has been learnt in training programmes. Caregivers report, for example, that aspects of a relationship between a caregiver and a partner with profound handicap such as shared games, gestures or routines may reappear spontaneously in people with profound handicap when they are reunited with a carer after a long period of separation. This is noticeably different from learning in a behaviour modification programme, which disappears unless regularly reinforced. Given these differences, and the tremendous problems in training people with profound handicap, it is conceivable that a consideration of the nature of profound mental handicap, with special attention given to these incidents of learning, may even improve the techniques used in training.

It could be argued, in fact, that given the time and expense put into training programmes, and the uncertainty of achieving lasting positive results, it may be more effective to set out to improve the quality of life more directly. Movement therapy, for example, builds upon the communicative skills which people with profound handicap already have and are already using. Cleland (1979a) has offered the provocative idea that it is possible that many people with profound handicap don't enjoy training programmes very much and, if we could ask them, would prefer not to be trained to use a knife and fork rather than fingers or a spoon, for example. I would not necessarily argue for this, but it does seem that a balanced and more thorough approach to profound mental handicap is long overdue.

The first step in this is to actually describe what behaviours are seen in people with profound handicap. In this, it is important to focus on behaviours which occur in the natural environment. If studies are restricted to artificial situations there is a danger that the behaviours observed and the conclusions reached will not be representative of the behaviour of people with profound handicap, and will have little practical value (Brooks and Baumeister, 1977). Comparisons with infant behaviour suggests that the emphasis of such study needs to be on communication and emotion. These aspects have been neglected in serious study in the past, but they are of the utmost importance. Such behaviours are also valued extremely highly by parents and carers and this should not be underestimated. In effect, they represent the personality of the individual, and to have the presence of such a capacity for individuality in people with profound handicap recognized is of obvious value to their carers.

In the study of the behaviours of people with profound handicap which follows, the framework I have used is a developmental one which takes into account the development of emotions and early communication. Developmental theory is undoubtedly the most useful in providing a framework for understanding the behaviour of people with profound handicap. Unfortunately, as I have shown, a cognitive developmental theory as it is usually applied to profound mental handicap does not take into account all that we know about early development. We must also include components of developmental theory which describe the early social development of infants, which may actually have more relevance for the study of people with profound handicap. Research into mother-infant interactions has provided a guide to the behaviours which it may be useful to look at in people with profound handicap, and this work forms the core of this thesis.

This framework has been important in three ways. First, the comparison with infant behaviour has suggested which of the behaviours of people with profound handicap may be the most important. It has also provided speculations on the biology of profound mental handicap, and the potential development of abilities.

Second, it has shown the best way to examine these behaviours: to film them on video and subject the tapes to micro-analysis. In fact, the dynamic processes which occur in interaction are such that this method is almost essential, and it has obvious advantages over less subtle techniques such as time-sampling or pencil and paper description of on-going behaviour in predefined categories. This is reflected in the vast increase in our knowledge of mother-infant interactions which followed the widespread introduction of video-analysis techniques. This approach has so far not been attempted in any study concerning people with profound handicap.

Thirdly, this framework has also provided a basis with which to attempt to understand the behaviour of people with profound handicap. In practice, this was in two ways: providing a timescale of development within which to place and compare the behaviour of people with profound handicap, and providing a possible explanation for isolated aspects.

This, then, is the main theoretical background to this research. In addition, I have found a second approach useful at all stages: the ethological technique used by Cleland and his colleagues. They have shown that collecting data in the form of examples of behaviour, obtained either by direct observation or from staff that work with the subjects, may be a very valuable source of information. Above all, Cleland has demonstrated the value of considering a behaviour in context. With his work in mind, I used two questionnaires (one formal and one informal) as part of the methods for data collection in this research.

The descriptive approach taken in this research has provided a guide to what to look at, how to look at it, and may offer explanation of the results. A detailed description of the methods used in this research follows in the next chapter.

## CHAPTER 5. METHOD

### 1. Subjects

In Developmental Psychology it is possible to draw conclusions, with appropriate caution, from research based on few subjects. Similarly, in mental handicap children with Down's Syndrome are often studied because they all have an identifiable cause of handicap, and results from a study using a small sample may be generalized to the Down's Syndrome population.

Working within the diverse and poorly understood category of profound mental handicap, however, extreme caution has to be shown in generalizing results. People with profound handicap differ across a great many variables, including cause, aetiology, age, sex, place of residence, degree of physical handicap, degree of sensory handicap, degree of epilepsy, amount of behavioural problems, and countless others. Clearly, a study involving only a small number of subjects could not be seen as representative. As there are so few people with profound handicap in the general population, obtaining a large sample presents a serious problem. In this study I decided to include as many subjects as I could in order to obtain a representative sample of profound mental handicap. Also, I considered it important to draw subjects both from those resident in hospitals and those resident with families in the community, as this is a potentially important - and often neglected - variable.

#### *1.1 Subject Selection*

All subjects in this research had been classified by the services with which they were in contact as having a profound handicap. Although I carried out no formal testing, observation and discussion with carers confirmed that the subjects were functioning at a level of ability defined by the AAMD as profound mental handicap (i.e. mental age less than 3.1 years), that their characteristics matched those outlined by Presland (1982) (i.e. virtual absence of expressive and receptive language, poor self help skills, and in some cases the presence sensory or motor deficits), and that the level of care corresponded to that of level IV as defined by the National Development Team (1985) (i.e. the highest level of dependency). Additional criteria for this research, outlined in Chapter 2, included the absence or virtual absence of any formal

or symbolic communication such as speech or sign systems. This ensured that no subjects came from the higher ability ranges of people with a profound handicap.

The subjects in this research were sought mostly from Edinburgh and the administrative region of Lothian, in south-east Scotland. This area has a population of three quarters of a million people, and comprises a mix of some very affluent and some very poor districts. The main centres of population are: Edinburgh and its suburbs, Dalkieth in Mid Lothian, Bathgate and the new town of Livingston in West Lothian, and Haddington, Musselburgh and Prestonpans in East Lothian. Subjects included in this research were from a wide range of geographical locations and social classes.

Initially, I conducted a brief survey of facilities for people with profound handicap in Edinburgh and West-, Mid-, and East Lothian. Within this area, there are five special schools which have at least one pupil with a profound handicap; six adult training centres with special care units which in principle may cater for people with profound handicap; one day centre for the physically handicapped run by the Scottish Council for Spastics; and four mental handicap hospitals which have residents who have a profound handicap. In addition, social services run several schemes offering respite care within families or at one of three short stay hostels, and there are many local parent support groups and voluntary organisations. There are also individuals working in mental handicap in the community, in social work area teams and in clinical psychology.

All of these potential sources were written to, outlining the research and asking for assistance in locating subjects with a profound handicap. An information sheet was prepared and copies sent to different organisations, with a request to circulate it amongst professionals and parents. From later feedback, this evidently had a very wide circulation, finding its way into social work area team meetings and onto school notice-boards. The response was encouraging, and I visited all of the schools, centres and hospitals, and the majority of organisations.

The number of children with profound handicap in the schools varied from fifteen to four. Of the adult training centres, only three of the special care units had trainees with a profound handicap (with a maximum of six per unit). All four hospitals



had sizeable populations of people with profound handicap. In addition, social services were in contact with many families of children with profound handicap.

Visiting each school, I presented the criteria for subject inclusion and discussed this with the teachers. The children that matched this criteria were then identified. In order to protect the privacy of the families, I decided not to write to the parents directly, but instead sent a letter through the school. This outlined the research and asked for their participation, including a stamped addressed envelope for the replies. A similar procedure was adopted in the training centres.

Social services and voluntary organisations sent information about the research to parents, but here it was not possible for me to meet individuals first. Two positive replies were rejected after home visits as not meeting the selection criteria.

Through these sources I wrote to every family of individuals with profound handicap who were resident at home of which I had knowledge (with the exception of one family not written to on the advice of professionals, due to a family crisis).

The position regarding residents of hospitals was slightly different, as the staff would be needed to participate in the research and not the parents. First, approval for the research to use subjects resident in hospital was obtained from the Area Health Authority Ethics of Research Committee. Then I visited the hospitals to discuss the research with staff, to present the inclusion criteria, and to meet residents. Because of restrictions on the time that staff would have available to take part in the research, it was not possible to include all residents. In practice, it was only possible to include approximately one third of the suitable residents on each ward. This selection was made jointly by the staff and myself, and within limits imposed by the setting (i.e. availability of resident and staff), attempted to be as random as possible. It is stressed that residents were not picked for their communicative ability. Only one additional criteria was used: that the subjects had not taken part in the earlier 'Moving in Sympathy' research. After the selection of suitable subjects, letters to parents asking for their consent to the research were sent.

Consent was obtained from parents of subjects in hospital in 95% of cases. The other 5% of potential subjects were not used. Unfortunately, one of the hospitals could not be included in the research because the unit which housed residents with

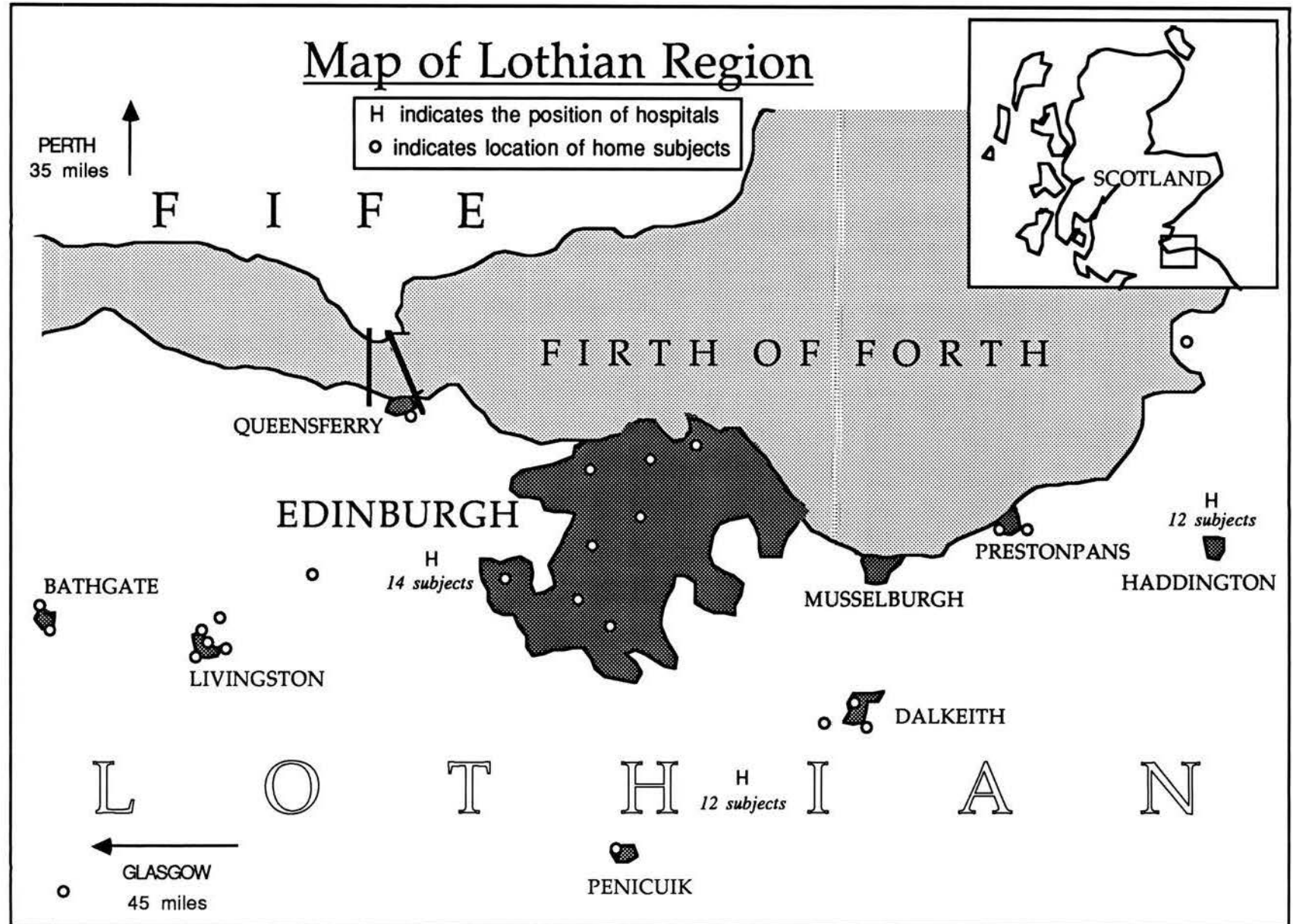
profound handicap was in the process of moving to a (controversial) new location. Residents from all of the other three hospitals took part.

For the subjects resident at home, 40% of the parents that were written to offered to participate in the research. Although most subjects were drawn from the Edinburgh and Lothian geographical region, three subjects who did not live locally (but who attended school in Edinburgh) were also included. These subjects lived in Glasgow, Fife and Perth. A map of Lothian is presented (over) which shows the major centres of population in the area, together with the locations of the home subjects and the hospitals in which other subjects were resident.

A total of sixty-six subjects with profound handicap were included in the research. In the course of obtaining these subjects, I estimate that I have identified around one hundred children and adults with profound handicap in the community in the Lothian area, and around one hundred and fifty in Hospital. It is not clear how accurate this is as a figure for the total population of those with profound handicap in the area. The total population of Lothian from the most recent census is as follows:

East Lothian	80 838
Mid Lothian	83 362
West Lothian	140 700
<u>Edinburgh</u>	<u>440 902</u>
Total	744 802

There are no official estimates for the numbers of people with profound handicap in these figures, but if my total of 250 is used, a prevalence rate of .0003 is obtained. Considering the low ability range of the sample, the wide age ranges of the subjects I have identified and the generally low life expectancy in profound mental handicap, and taking into account the young ages of subjects in most epidemiological studies (the prevalence rate in children will be higher), this may represent a fairly accurate estimate. As I have included 63 of the subjects identified in Lothian, I have therefore obtained a sample of approximately 25% of the potential subjects in the area.



## *1.2 Representativeness of the Sample*

Because of the restrictions imposed on subject selection (principally the reliance on permission from parents), final selection was not random and it could be argued that parents of an individual considered less able would not take part because they felt their children would perform badly. In practice, I do not think that this was the case. In the hospital subjects, there were very few refusals to grant consent, so this criticism can only be applied to the selection of home subjects. Here, I found that many of the subjects included in the research were amongst the most handicapped I had observed, and parents did not seem to be afraid of their children 'doing nothing'. In fact, it is impossible in most cases to know why some parents refused permission to film, but I believe that the most likely reasons were lack of time and an unwillingness on their part to be filmed, both of which are quite understandable. In several instances parents wrote to me giving the reasons for a refusal, and these featured prominently. Given this, I do not think that relying on parental approval affected the ability level of the sample. Thus, though the sample was not random, it was representative of people with a profound mental handicap.

There are a great many variables within the population of people with profound handicap. The major ones are: residence (living at home or in an institution); age (specifically children or adults - aged over or under 16); presence of a motor handicap (ambulant or non-ambulant); and presence of a sensory handicap (blindness or deafness). The variations in these are all accounted for in the sample used in this research, the subjects being obtained from hospitals and the community, and featuring a wide range of ages and physical and sensory handicaps. Differences in provision in Lothian Region, for example the numbers living in institutions, mean that the prevalence of many of these variables in the subject population will be quite different from other areas, but their presence generally is typical of people with profound handicap as a whole.

The dimensions of the subject population are outlined in further detail in the results section.

## 2. Procedure

There are a great many aspects of the behaviour of people with profound handicap worth studying. With such a comparatively large number of subjects, and in conditions where there would be a limited amount of time available to spend with each subject (hospital wards, for example, are busy and understaffed and I would need to take staff away from other duties), I needed to extract the maximum amount of data possible in a short space of time. This was achieved by using two methods of data collection. The first technique was to use a portable video camera to film the subjects interacting with a familiar caregiver (a parent or known member of staff), and to analyse this later. This was the procedure that I had intended to use from the first stage of planning the research. The only drawback to this is that the behaviour that a subject does not display in front of the camera is not taken into account. I did not know how much information would be lost through this, but decided that a way to take account of such a loss was by including a second technique as part of the design: a questionnaire on the subject's behaviour to be administered to the caregiver. This was later changed to include two questionnaires, a formal and an informal one.

### 2.1 Filming

For home visits, and for two of the hospitals, the filming was conducted using a small portable video camera. One of the hospitals had a purpose built, sound proofed studio (constructed for the 'Moving in Sympathy' project) which enabled filming by two cameras operated from an adjacent control room. In the other two hospitals filming took place in an empty, closed room close to the subject's ward. Filming at home took place as far as possible in a quiet room of the house away from other people.

Subjects at home were filmed with the mother in all cases except two. One subject lives with her older sister and was filmed with her. The other subject was filmed with her adoptive mother. Subjects in hospital were filmed with a familiar caregiver. Where possible this was the subject's favourite or most familiar caregiver.

Subjects were each filmed on two separate occasions, at least two weeks apart. This was to ensure that the films would be less biased by chance fluctuations in mood.



All home subjects were filmed with the same caretaker. For several hospital subjects this was not possible because of the unavailability of the staff (through transfer, leave, different shifts, or pressure of work) and another equally known caregiver was substituted. One subject was filmed only once due to her subsequent illness. Each filming session was planned to last ten minutes. Some sessions lasted longer, and a few had to be halted sooner.

Caregivers were all instructed to treat the session as extra time alone with the subject and to do whatever they would normally do. I explained that I was interested in whatever the subject did, including communication, and agreed to any suggestion of activities from the caregiver. In practice most caregivers chose to play with the subject, and there was attempted interaction in every session.

It is difficult to assess how much the camera and the situation itself influenced behaviour. There were two possible effects: that of the filming, and of my physical presence during the session. Although the camera had no evident effect on the behaviour of the subjects with profound handicap, it is possible that some may have reacted to my presence, and as far as was possible this was recorded in the first questionnaire<sup>1</sup>. It is harder to judge the effect on carers, but they all seemed able to forget me and the camera to some degree. There has actually been some research on this issue (Barton and Brulle, 1983), which found that in most cases an observer did not have any great effect on the behaviour of people with profound handicap and their carers, but that much depended on the situation and the tasks they were performing.

Obviously, the filmings that took place in the purpose-built studio represent the ideal situation and minimized these problems. In the other filmings, care was taken to relax subjects and caretakers before filming and familiarize them with the camera. Also, the very small size of the camera helped the caregivers to forget that they were being filmed. The greatest asset, however, was the subject who monopolized the attention of all caregivers to varying degrees. It is also worth noting that most carers and subjects seemed to greatly enjoy the session.

It was impossible to be sure that all subjects and carers had the same exposure to me and the camera before filming began. Typically, mothers interact with their

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<sup>1</sup>In the event, no carers thought that my presence significantly altered the subject's behaviour once the session was underway

children almost constantly, and for most of the home visits, and many of the hospital subjects, pin-pointing the exact moment a session began is meaningless. Therefore the beginning of the filmed record cannot be seen as the beginning of the engagements between carer and subject that occurred in my presence. In practice, judging by carers' comments and notes taken during filmings, the time I allowed for familiarization with the situation before filming was enough for all carers to adjust and settle down as much as they were going to do.

## 2.2 Questionnaires

I gave all caregivers two orally presented questionnaires. These were based on an initial questionnaire which I piloted on six carers participating in the 'moving in sympathy' research. Responses to this questionnaire shaped the topics included in the later questionnaires, and also the methods used: to extract the maximum amount of information it was necessary to use both a formal and a more informal, anecdotal approach.

The first of these questionnaires was in the form of a planned interview. It was conducted on the first visit to the subject and taped on a portable tape recorder. It lasted an average of thirty to forty minutes. The questionnaire covered the following points:

1. Whether the behaviours seen during the visit were typical.
2. Self help skills.
3. Ways in which subject communicates.
4. Moods and emotions of subjects; whether any of these are predictable.
5. Reactions to people and places.
6. Sense of humour of subjects; what they laugh at; how often.
7. Sensitivity to mood of others.
8. Liking for music.
9. Regularity of sleep cycle.
10. Subject's anticipation of daily routine/learning/ attempts to control the environment.
11. How subject has changed over the years.
12. General views on profound mental handicap; how they communicate.

Other topics such as age, medication and known aetiology were also covered. The subjects behaviour and response to me was noted.

The purpose of this interview was to gather background knowledge for each of the subjects and build up a general picture of their day to day behaviour. The

interviews were transcribed after the visit, and from these a number of relevant examples of behaviour will be described later. This questionnaire also served as an introduction to a more extensive and more specific second questionnaire.

The second questionnaire was administered on the second visit and lasted an average of thirty minutes. This questionnaire took the form of sixty three questions, each having five alternative answers on a fixed five point rating scale. (The questionnaire is reproduced in full in appendix IV). Most questions required a rating of frequency, for which the following guide-line was given:

1. never: event never happens.
2. rare: event happens over weeks/months/rarer.
3. occasionally: event happens over days/week.
4. often: event happens over day.
5. very often: event happens over much of day.

A summary of each question, with the range for the rating in the right hand column, and further explanation if necessary, is given below:

01. SEX	'male' or 'female', rated 1 or 5 only.
02. AGE	Rated in years.
03. RESIDENCE	'home' or 'hospital', rated 1 or 5 only.
04. ANTI-EPILEPTIC DRUGS )	
05. PHENOBARBITONE )	All rated from: 'one or two different drugs -
06. BENZODIAZEPINE DRUGS )	high dosage' to 'no medication.
07. PSYCHIATRIC DRUGS)	
<i>(Ratings were obtained by noting the exact amount and type of medication for each subject and later having these categorised and rated independently by a consultant psychiatrist)</i>	
08. EPILEPSY	'frequent/serious fits' to 'not known epileptic'
09. SLEEP DISTURBANCE	'very often' to 'never'
10. MOBILITY	'cannot move' on own to 'can walk unaided'
11. VISUAL HANDICAP	'blind' to 'no handicap'
12. AUDITORY HANDICAP	'deaf' to 'no handicap'
13. HEAD CONTROL	'no head control' to 'good head control'
14. VISUAL TRACKING	'no visual tracking' to 'good visual tracking'
15. HAND CONTROL	'no use of hands' to 'good use of hands'
16. STEREOTOPY	'very often' to 'never'
17. SELF-INJURY	'very often' to 'never'
18. SELF HELP SKILLS	'none' to 'most skills, unaided'
19. SPONTANEOUS LEARNING	'none' to 'very often shows spontaneous learning'
<i>(Used learning and anticipation of the daily routine as an example)</i>	
20. KNOWS CAUSE-EFFECT	'never' to 'often demonstrates'
<i>(Used jack in the box toys or switches as examples)</i>	
21. REFUSES TO OBEY CARER	'very often' to 'never'
22. ACTIVITY	'very often' to 'never active'
23. AWARENESS	'very often' to 'never aware'
24. RESPONSIVENESS	'very often' to 'never responsive'
25. ORIENTS TO PERSON	'very often' to 'never'
26. ORIENTS TO EVENT	'very often' to 'never'

27. ATTENTION SPAN	'long attention span' to 'never attends'
28. INTEREST IN OBJECTS	'very often' to 'never'
29. PUTS OBJECTS IN MOUTH	'very often' to 'never'
30. RESPONSE TO INDIVIDUALS	'no people' to 'all, especially well known'
31. ACTS ON ANOTHER PERSON	'very often' to 'never'
<i>(Acts on another defined as instances where subject obtains desired event/ object by influencing partner to act)</i>	
32. INITIATES INTERACTION	'very often' to 'never'
33. SHUNS INTERACTION	'very often' to 'never'
34. GIVES EYE CONTACT	'very often' to 'never'
35. PHYSICAL CONTACT	'very often likes it will initiate it' to 'never likes it'
36. PROXIMITY	'typically likes being very close' to 'far away'
37. MAKES SOUNDS	'very often' to 'never'
38. VARIETY OF SOUNDS	'very many different sounds' to 'no sounds'
39. USE OF WORDS	'very often' to 'never'
<i>(In all cases, use of words was inappropriate)</i>	
40. USE OF YES/NO	'very often' to 'never'
<i>(Appropriate use specified, vocal or signed)</i>	
41. TURN TAKING	'very often' to 'never'
<i>(use of sounds in a conversation-like turn-taking pattern)</i>	
42. IMITATION OF PARTNER	'very often' to 'never'
43. FACIAL EXPRESSION	'very often' to 'never':
<i>(Frequency of a facial expression)</i>	
44. EMOTIONS i. HAPPINESS	'very often' to 'never':
<i>(Frequency of a happy facial expression)</i>	
45. EMOTIONS ii. SADNESS	'very often' to 'never'
<i>(Frequency of a sad facial expression)</i>	
46. EMOTIONS iii. ANGER	'very often' to 'never'
<i>(Frequency of an angry facial expression)</i>	
47. EMOTIONS iv. FEAR	'very often' to 'never'
<i>(Frequency of a fearful facial expression)</i>	
48. APPROPRIATE LAUGHTER	'very often' to 'never'
49. APPROPRIATE SMILING	'very often' to 'never'
50. INAPPROPRIATE LAUGHTER	'very often' to 'never'
51. INAPPROPRIATE SMILING	'very often' to 'never'
52. CRIES	'very often' to 'never'
53. CHANGES IN MOOD	'very often' to 'never'
54. MOOD EXPRESSION	'dramatic differences' to 'no differences between moods'
55. FEAR OF STRANGERS	'very often' to 'never'
56. FEAR OF UNFAMILIAR SITUATION	'very often' to 'never'
<i>(Fear of a strange situation)</i>	
57. EMOTIONAL SENSITIVITY	'very often' to 'never'
<i>(Sensitivity to the emotions of others)</i>	
58. LAUGHTER AT EMOTIONAL OUTBURST	'very often' to 'never'
<i>(Laughter at an emotional outburst by another person)</i>	
59. LAUGHTER AT TEASING	'very often' to 'never'
60. RESPONSE TO ANGER	'very often' to 'never'
<i>(Response to an angry voice)</i>	
61. LIKING FOR PEOPLE	'very strongly' to 'none'
<i>(An expressed liking for people)</i>	
62. LIKING FOR MUSIC	'very strongly' to 'none'
<i>(An expressed liking for music)</i>	
63. LIKING FOR TRAVEL	'very strongly' to 'none'
<i>(An expressed liking for travel e.g. in a car)</i>	

The answers gathered from this second questionnaire were intended to get a picture of the broad characteristics of people with profound handicap, and for statistical analysis.

### 3. Analysis

#### 3.1 Video Tape

At the completion of filming I had over twenty hours of tape. In order to attempt a thorough analysis of each subject's session, my first task was to edit down the amount of tape to a manageable length. I decided that ten minutes per subject would enable a detailed analysis of all subjects. I also decided that the film to be analysed should not be chosen according to quality or content, but taken from a similar part of the tape for all subjects.

Five minutes from each session were edited onto a separate tape for analysis. In all cases the five minutes taken were the first five minutes filmed from each session. The reasons for this were that all sessions had lasted at least five minutes so the same part of the film could be used for all subjects. There was therefore no possibility of bias in the selection. I had originally intended to use the second five minutes from the second session reasoning that the carer might appear less nervous later into the session, but (as mentioned above) as the beginning of filming did not coincide with the beginning of the session this made this precaution less important than obtaining the same sample of tape for all subjects, including the small minority where the second session was interrupted before ten minutes had been taped. In order to ascertain what effect exposure to the filming had on the carers, a comparison was made between the first five minutes in the first and second session.

The analysis of the ten minutes of tape for each subject consisted of measurement or calculation of the following variables:

#### 1. PARTNER'S ENGAGEMENT WITH SUBJECT (measured in seconds):

- a. *total time partner engaged with subject.*
- b. *total time partner used an object in an attempt to obtain engagement.*
- c. *total time partner used food in an attempt to obtain engagement.*
- d. *total time partner used physical contact in an attempt to obtain engagement.*
- e. *total time partner used active physical contact<sup>2</sup> to obtain engagement.*

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<sup>2</sup>Use of active physical contact refers to active behaviours such as patting, stroking, rubbing, or



2. SUBJECT'S ENGAGEMENT (seconds):
  - a. *total time engaged with partner.*
  - b. *total time engaged with partner using an object.*
  - c. *total time engaged with partner using food.*
  - d. *total time engaged with partner using physical contact.*
  - e. *total time engaged with partner using active physical contact.*
  - f. *total time engaged with an object.*
  - g. *total time engaged in actively resisting partners attention.*
  - h. *total time engaged with another event.*
  - i. *total time engaged.*
3. EVENT PRECEDING EACH PERIOD OF ENGAGEMENT (number):
  - a. *event is: partner attempting engagement using vocalizations only.*
  - b. *event is: partner attempting engagement using object.*
  - c. *event is: partner attempting engagement using food.*
  - d. *event is: partner attempting engagement using physical contact.*
  - e. *event is: partner attempting engagement teasing.*
  - f. *event is unknown.*
4. NUMBER OF ENGAGEMENTS (number).
5. NUMBER OF INITIATIONS OF ENGAGEMENTS BY THE SUBJECT (number)
6. NUMBER OF TERMINATIONS OF ENGAGEMENTS BY THE SUBJECT (number)
7. AMOUNT OF EYE CONTACT GIVEN BY THE SUBJECT (seconds).
8. AMOUNT OF PHYSICAL CONTACT INITIATED BY SUBJECT (number).
  - a. *subject touches*
  - b. *subject pushes*
  - c. *subject scratches*
9. AMOUNT OF FACIAL EXPRESSION (seconds).
  - a. *total.*
  - b. *happy facial expression.*
  - c. *sad facial expression.*
  - d. *angry facial expression.*
  - e. *fearful facial expression.*
10. AMOUNT OF CRYING (seconds).
11. AMOUNT OF LAUGHING AND SMILING (seconds)
  - a. *appropriate laughter.*
  - b. *inappropriate laughter.*
  - c. *appropriate smiling.*
  - d. *inappropriate smiling.*
12. AMOUNT OF LAUGHING AT TEASING BY THE CARER (number).
13. AMOUNT OF LAUGHING AT AN EMOTIONAL OUTBURST BY CARER (number).
14. AMOUNT OF TIME SUBJECT MADE SOUNDS (seconds).
15. NUMBER OF DIFFERENT SOUNDS USED (number)
16. NUMBER OF SOUNDS MADE DURING ENGAGEMENTS (% of total sounds).
17. NUMBER OF WORDS USED (number)

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swinging, as opposed to 'physical contact' which refers to physically supporting or inactive touching.

18. TOTAL TIME SUBJECT INTERESTED IN OBJECTS<sup>3</sup> (seconds).
19. TOTAL TIME OBJECT IS MOUTHED (seconds).
20. DURATION OF STEREOTYPED BEHAVIOUR (seconds).
21. DURATION OF SELF-INJURIOUS BEHAVIOUR (seconds).
22. NUMBER OF TIMES SUBJECT ACTS ON ANOTHER FOR AN EVENT (number)
23. NUMBER OF TIMES SUBJECT DEMONSTRATES A LEARNED ACTION (number)
24. NUMBER OF TIMES SUBJECT IMITATES PARTNER (number)
25. NUMBER OF TIMES SUBJECT'S MOOD CHANGES DURING SESSION (number)

A figure for items 2., 3., 4., and 16. was also obtained separately for engagements where subjects actively resisted the partners attempts at engagement. This was a considerable problem to categorize. Clearly, the subject was engaged with the carer, but equally clearly this was a different kind of engagement, typified by biting or scratching, and sometimes considerable emotional disturbance. I have termed such engagements 'negative engagement' or 'resisted engagement'.

The definition of engagement is important for this analysis, and most of the variables measured were dependant upon a reliable definition. In this research, I devised and used the following:

#### A. Beginning of Engagement:

- i Orientation of head towards partner or object held by partner
- ii Change in at least one behaviour (e.g. facial expression, eye contact, manipulation of an object, soundmaking)

#### B. Continuation of Engagement:

- i Continuation of at least one behaviour (e.g. facial expression) dependant on actions of partner

#### C. Ending of Engagement:

- i Orientation of head away from partner or object held by partner
- ii Change in at least one behaviour (e.g. facial expression, eye contact, manipulation of an object, soundmaking) including the extinction of the prime component behaviour of the engagement (as described in B. i)

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<sup>3</sup>This figure adds the time that the subject attended to an object alone with the time the subject attended to an object used by the carer.

This was sufficient for most subjects, although in blind subjects the head does not always turn directly to the partner when there is engagement. Similarly, for subjects who are severely restricted in movement and/or able to express themselves very little, A. ii may be represented by A.i. or vice versa. Generally, these 'rules of engagement' defined the presence or absence of an engagement for all subjects, and seemed to work well.

The process of performing an analysis of the tapes using the categories listed above was extremely time consuming, but the results were exhaustive. The technique used was to firstly superimpose a digital time display in seconds and milliseconds onto the tape, then to notate all events giving the time of the beginning, the end, and the duration. Separate columns were used for each category. A sample transcription (much simplified) is presented in Table 5.1 (over), which represents the first five minutes of a session.

In the sample video analysis, the carer is described on the left, the subject on the right. The columns represent the times and duration of periods of the following behaviours: the carer's engagement or attempted engagement with the subject; use of physical contact, active physical contact or objects to obtain engagement; the engagement of the subject to the carer, other events or objects; the subject's facial expressions; and the subject's eye contact.

The numbers indicate the times of the start and end of the behaviours specified in the column. A total is given next to them. At the bottom, totals are given for each column. Thus, we can see that the carer tried to engage for 296 seconds, using an object for 135 seconds, and active physical contact for 75 seconds. The subject engaged for 143 seconds, of which 133 seconds was while the carer used an object, and 75 seconds while he used active physical contact (they were both therefore successful techniques). The subjects used a facial expression (in this case all smiling) for 15 seconds. Additional information is given next to the figures for the subjects engagements. A letter next to the time the engagement started indicates the behaviour of the carer just before (i.e. physical contact, used an object etc.). The letter next to the time the engagement ended indicates whether the subject terminated it (shunned = s) or whether there was another reason (-). This analysis was performed on the tapes of sessions for all sixty-six subjects, taking on average between 120 and 180 minutes to complete for each subject.



#### **4. Statistical Analysis of the Results**

Data from the second questionnaire and the video analysis was analysed in several ways. First, a profile of the subjects as a group was obtained according to their scores upon each of the questions in the questionnaire and the video analysis categories. This gives an impression of the range and frequency of a variety of behaviours in people with profound handicap. Second, analysis was performed to see if factors such as medication and physical or sensory handicap have any significant effect on behaviour as measured in this study. Lastly, factor analysis was performed on both sets of data to identify the underlying factors contributing most to the results (factors which are important in the behaviour of people with profound handicap), and cluster analysis was performed to see if the subjects cluster into groups, and if so which variables discriminate between them.

These results are presented in Chapter 6.



## CHAPTER 6. RESULTS

The results in this section are presented in the following order: first, a general description of the subject's physical characteristics; second, the initial results of the second questionnaire, supplemented with material from the first questionnaire; third, the initial results from the video analysis which, together with the questionnaire results, offer a profile of the behavioural characteristics of people with profound handicap; and lastly, further statistics based on these initial results.

Before the results are given, however, I will present the results of the reliability checks performed on the methods of data collection.

### **1. Reliability**

The reliability of the questionnaires is very hard to establish. Basically, I had no independent way to be sure that carers were giving accurate and honest reports, but my impression is that they were. This receives some support from the fact that many carers reported quite negative behaviours in the subjects and seemed to have a very realistic view of their abilities.

The only research which has some relevance is a study by Appell and McKeen (1974) which compared the ratings of parents and professionals of the performance of subjects with severe or profound handicap on developmental tasks. They found that the ratings were reliable overall, though there was a tendency amongst some parents to rate performance on a few tasks higher than they should. These tasks were those which were more personal and less to do with cognitive ability. Aware of this possible tendency, I looked for any high ratings which seemed incongruous with other ratings or my own observations of the subject. I found no instances of this.

Having said this, it must also be remembered that carers could have been wrong in their ratings: they could have assumed the presence of a behaviour which is not there by misinterpreting an action or simply forgetting; or they could have assumed a behaviour is not present when it is present because they have not seen it occur. On the whole I am happy that the questionnaires represent an accurate reflection of the characteristics of the subjects.

For the video analysis, reliability coefficients were obtained. I also compared the two sessions which were recorded for each subject to see if exposure to the situation had any effect on the levels of engagement. Using only subjects who had had the same carer for the two sessions and where the two sessions were of identical length, I found that the totals for engagement were almost the same (the difference between them was 6.02%), with the total for the first session having the higher figure. There therefore does not appear to be any significant difference between the two session.

The video analysis was checked for reliability by using a second rater, experienced in mental handicap. This rater was given the coding procedure and rules of engagement, and, after practising the procedure on one subject, rated six subjects (9% of the population) chosen at random. These independent ratings were compared with the ratings I had obtained previously. Ratings for all categories were compared using the following formula for the reliability coefficient:

$$1 - \frac{\text{difference} \times 100}{\text{total}}$$

The coding sheets of both observers were compared and for each category a figure was obtained for the agreement between them, and figures calculated for their two separate totals. In the coefficient, the two totals are added to get the 'total' in the equation, and the 'difference' is obtained by the subtraction of the figure for agreement from the total which is most different.

Reliabilities are given in Table 6.1 and discussed below. In almost every case my own coding gave a lower score than the other rater. My coding therefore appeared to be more strictly applied.

The variables involving the partner all achieved high reliability. 'Partner's total engagement' had coefficients ranging from 100 to 97 (mean: 99); 'engagement using objects' (where used) 89.7 to 96.7 (96.1); 'engagement using physical contact' 88.2 to 98 (94); 'engagement using active physical contact' 86 to 94.1 (89.4); and 'engagement using food' (where used) 88.4 to 98.9 (94).

CATEGORY	SAMPLE PRESENT IN RELIABILITY			RANGE
Partner's Total Engagement	6	6	99.0	97.0-100
- Using Physical Contact	6	6	94.0	88.2-98.0
- Using Active Phys. Cont.	6	6	89.4	86.0-94.1
- Using Objects	6	4	96.1	89.7-96.7
- Using Food	6	4	94.0	88.4-98.9
Subject's Engagement to Partner	6	6	91.9	83.6-98.2
- Resisted Engagements	6	2	85.4	70.9-100
- To Objects	6	3	91.6	87.3-98.9
- To Other Events	6	3	74.0	64.9-81.2
No. Engagements: Beginnings	6	6	76.5	66.6-94.7
No. Engagements: Endings	6	6	73.8	33.3-89.5
Preceding Event to Eng.	6	6	55.4	00.0-100
Subject's Initiations	6	1	66.6	-
Subject's Terminations	6	6	74.2	53.8-86.7
Eye Contact	6	3	66.5	42.0-81.0
Happy Facial Expression	6	4	91.4	87.4-96.5
- Sad	7	1	78.3	-
- Angry	7	1	70.4	-
- Frightened	-	0	-	-
Crying	7	1	85.7	-
Appropriate Smiling	6	4	91.4	87.4-96.5
- Laughing	6	2	85.8	85.1-86.5
Inappropriate Smiling	7	1	85.5	-
- Laughter	7	1	80.0	-
Stereotopy	6	2	90.2	86.4-94.1
Self-Injury	7	1	95.3	-
Touches	6	3	74.5	50-93.6
Pushes	7	1	90.0	-
Scratches	7	1	100	-
No. Sounds Used	6	6	91.4	81.4-87.3
Words Used	6	1	90.9	-
Turn-Taking	6	1	87.5	-
Imitation	6	1	66.6	-
Learned Action	6	2	60.0	-
Acts on Partner	6	1	85.7	-

TABLE 6.1 RELIABILITY

*Sample of subjects used was 6 in most cases. Where a category did not appear in any of the 6, another subject was added to the sample, making 7. The number of subjects in the sample in which the category was present is given in the third column ('Present in'). 'Reliability' lists the mean reliability coefficient. The range of these for the sample is given in the last column.*

The subject's engagement to the partner, in many ways the most important variable, achieved coefficients ranging from 83.6 to 98.2 (mean: 91.9), which is also very acceptable. Similarly, there was agreement on the two subjects who resisted engagement, with the duration having reliability coefficients of 70.9 and 100. High coefficients were also obtained for the subject's 'engagement with objects' (range 87.3 to 98.9, mean: 91.6) and 'engagement to other events' (range 75.9 to 81.2, mean:).

There were some problems in estimating the reliability of the number of separate engagements, however. Although overall the two raters agreed on approximately the same number of engagements per session, there was some dispute over the exact times these engagements began and ended. This was reflected in the coefficients because of the way in which I checked the reliability of 'number of engagements': the coding sheets of the independent rater were compared to my own and the agreement for the times recorded for the beginning and end of each separate engagement was noted, allowing an additional three seconds for recording differences. This revealed that the beginnings of engagements had a coefficient ranging from 66.6 to 94.7 (mean: 76.5), and the endings from 33.3 to 89.5 (73.8). These were acceptable, but suggested that raters have some problems in distinguishing the exact moment of the beginning and end of an engagement. Comparing the coding sheets, I found that there was basic agreement on the times of the major periods of engagement but disagreements between raters over short breaks in them. For example, one rater might have a two second break where the other rater had none, and vice versa. This, I believe, accounts for the lower coefficients. Similar problems were encountered in the category of 'subject terminating engagement', which had overall coefficients ranging from 53.8 to 86.7 (mean: 74.2).

The 'preceding event to engagement' category proved less reliable in some ways. Overall the coefficient was only 55.4, and there was considerable variability between different 'preceding events'. This was due to two reasons. First, there were the same problems as encountered in the 'beginning of engagement' category, outlined above (i.e. the preceding events were determined for different times). Second, when the same engagement is in question, it is likely that on occasions the preceding event may not be very obvious. Sometimes, for example, it could be described as 'vocal' or 'use of object'. In view of these criticisms, I think it best to be cautious in interpreting results based on 'preceding events'.

Most other categories seemed to be coded reliably, although the low frequency of some categories does mean that in some cases the reliability coefficients were based on very few examples: some categories, for example, were seen in only one of the sample of subjects used in the reliability check, and occurred very few times. In these categories - 'use of words', 'turn-taking', 'imitation', 'Learned action' and 'acts on the partner' - reliability coefficients of 90.9, 87.5, 66.6, 60.0, and 85.7 were obtained, respectively. These are high figures considering the small number of examples (only 3 incidents of imitation were featured, for example) and indicate that

coding is reliable for these categories, though perhaps caution should be taken in interpreting results featuring these categories as the reliability check is based upon only one subject.

Some categories did not occur in any of the subjects in the sample, however. In these cases, I showed the independent rater sessions of subjects that did show these behaviours. This was necessary for only 9 categories: 'self-injury', 'pushes', 'scratches', 'angry' and 'sad' facial expressions, 'crying' and 'inappropriate smiling' and 'inappropriate laughter'. Again, the reliability coefficients obtained, which ranged from 70.4 to 100, seem high enough to be certain that they are reliably coded, though the number in the sample should be borne in mind.

For most categories, though, the sample was fairly large and agreement was high. Presence of stereotypy achieved a coefficient of 90.2; 'number of sounds used' obtained a coefficient of 91.4; and 'subject touches carer' had a coefficient of 74.5. There was complete agreement on the presence or absence of the most frequent facial expressions, including appropriate smiling and laughing which obtained coefficients with a mean of 91.4 and 85.8 respectively. Similarly, raters agreed on the presence of eye contact, though the reliability coefficient for the duration was only 66.5 (range 42 to 81).

Overall, the reliability coefficients were high - especially for the important categories - and suggest that the results of the video analysis are reliable.

One final comment concerning the reliability of both methods of data collection is to point out that though they have resulted in a large amount of information providing a comprehensive overview of the characteristics of profound mental handicap, the number of subjects relative to the number of variables is comparatively small. Sixty six is a large number of subjects with profound handicap but considerably smaller than the number of subjects used in psychological studies of personality. Since the personalities and behaviour of people with profound handicap may well be as complex or as variable as those of normal subjects, perhaps the low number should be kept in mind.



2. A General Description of the Subjects

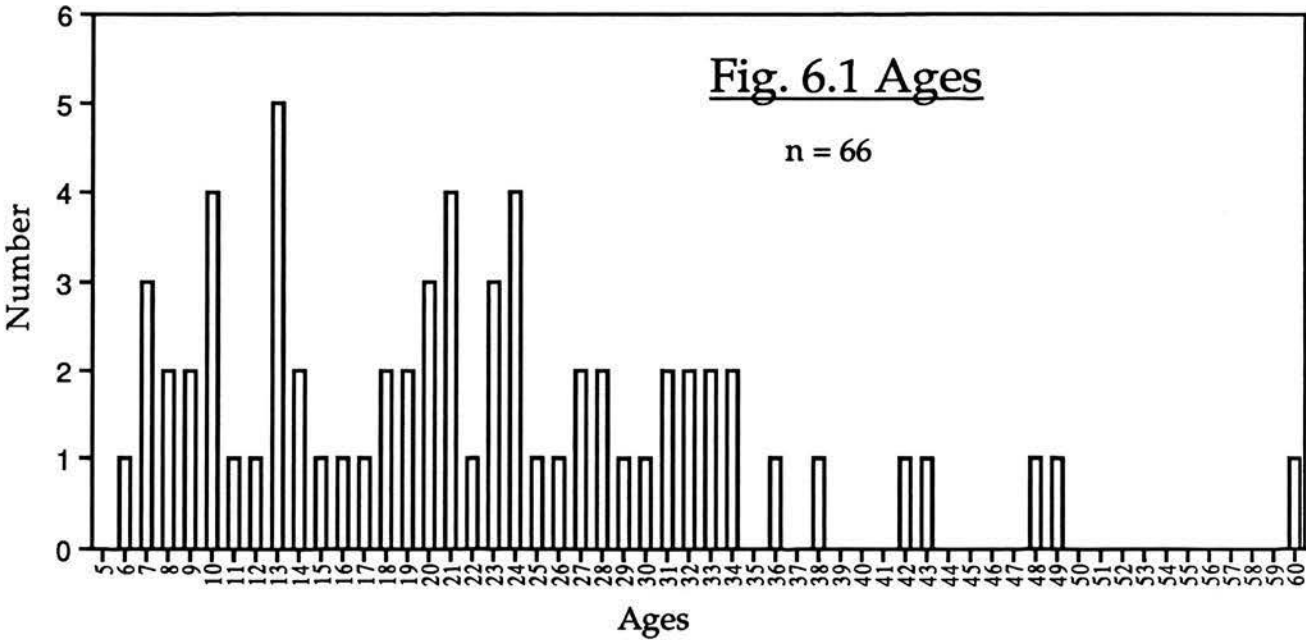
This description is based upon the responses to the second questionnaire, amended where relevant by medical records. Questions referring to physical condition were also confirmed by observation.

2.1 Sex

The subject population of 66 consisted of 34 males and 32 females.

2.2 Age

The ages of the subjects ranged from 6 to 60. The mean age was 22.2 years. On average, the younger subjects tended to be resident at home with their parents. There are a number of possible reasons for this which are mentioned in Chapter 7. The distribution of ages is shown in Figure 6.1.



2.3 Residence

38 of the subjects lived permanently in one of three hospitals, 28 of the subjects lived with their families in the community.

## 2.4 Aetiologies

Efforts were made to ascertain the background of the handicap for all subjects, and determine if a causal factor had been indicated. The results are shown below.

**Figure 6.2 Probable Causes of Profound Mental Handicap in each Subject**  
A '?' symbol indicates a high degree of uncertainty. 'Unknown' = no information on cause.

- |   |   |
|---|---|
| 1. Chromosome abnormality (genetic)           | 34. De Lange syndrome?                        |
| 2. Encephalitis/abnormal development in utero | 35. Unknown                                   |
| 3. Rett's syndrome (genetic)                  | 36. C.P.?                                     |
| 4. Unknown (brain damaged from birth)         | 37. Hypertelorism (genetic)                   |
| 5. C.P./microcephalus                         | 38. Microcephaly                              |
| 6. Unknown (probably genetic?)                | 39. Viral infection at 11 months              |
| 7. Premature birth                            | 40. Unknown                                   |
| 8. Viral infection at birth (herpes simplex)  | 41. Unknown                                   |
| 9. Head injury/hydrocephalus                  | 42. Unknown degenerative disease (metabolic?) |
| 10. Unknown                                   | 43. Perinatal asphyxia?/genetic?              |
| 11. Familial encephalopathy                   | 44. Meningitis at 8 years                     |
| 12. C.P./microcephalic                        | 45. Unknown, poss. reaction to immunisation   |
| 13. C.P./unknown                              | 46. C.P.?/San Filipo syndrome?/head injury?   |
| 14. Unknown                                   | 47. Unknown                                   |
| 15. Subarachnoid haemorrhage in first year    | 48. Unknown/spina bifida?                     |
| 16. Unknown                                   | 49. Genetic (chromosome translocation)        |
| 17. C.P./perinatal asphyxia                   | 50. Rubella                                   |
| 18. Unknown                                   | 51. Perinatal asphyxia?                       |
| 19. Unknown                                   | 52. Meningocele at birth                      |
| 20. Hydrocephalus at birth                    | 53. Premature birth?                          |
| 21. Unknown                                   | 54. Encephalocele/hydrocephalus/meningitis    |
| 22. Hydrocephalus                             | 55. Genetic (marriage between cousins)        |
| 23. Severe birth trauma                       | 56. Down's syndrome/thyroid problem           |
| 24. Genetic/difficult birth?                  | 57. Microcephaly/premature birth              |
| 25. Birth complications (forceps birth)       | 58. Down's syndrome/meningitis                |
| 26. Unknown (genetic?)                        | 59. C.P.?                                     |
| 27. Unknown                                   | 60. Gastro enteritis in year 1?               |
| 28. Unknown                                   | 61. Unknown                                   |
| 29. Microcephaly/primary cerebral thrombosis  | 62. Rett's syndrome (genetic)                 |
| 30. Hydrocephalus                             | 63. Unknown                                   |
| 31. Perinatal asphyxia                        | 64. Microcephalic                             |
| 32. Unknown                                   | 65. Infantile encephalopathy                  |
| 33. Unknown                                   | 66. Birth injury                              |

All information concerning hospital subjects was taken from their medical records. These yielded varying amounts of information depending on the ages of the subjects: for the older - who had been admitted over thirty years ago - the entry under 'cause of handicap' frequently read only 'profound mental handicap' or 'severe mental handicap'. The information for home subjects was obtained from parents. The majority knew the factors which contributed to the handicap, but several had no knowledge of these at all, nor, apparently, had any professional ever suggested any to them. Further information was obtained from the relevant school or centre.

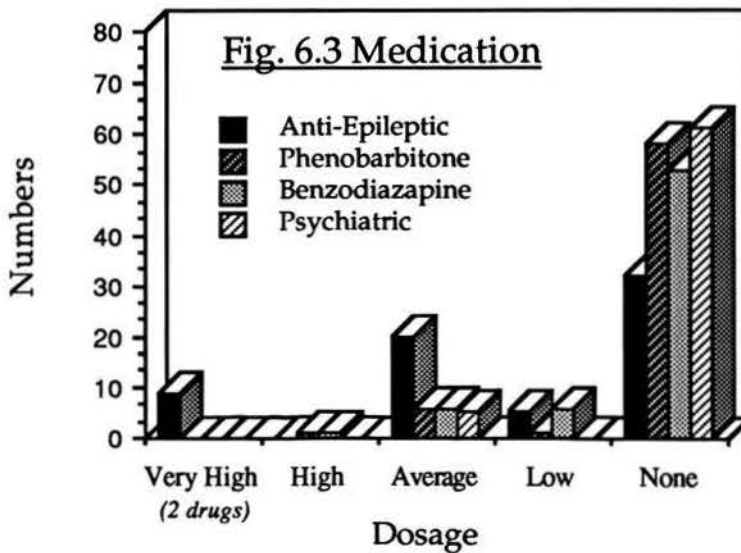
As can be seen from the table, many of the conditions listed next to each subject are not, in fact, indicators of a cause, but may represent a secondary effect of the cause, or a contributing factor. An example of this is 'birth complications', which is often cited as a cause but may actually be the result of an unidentified condition. In fact, of the 66 subjects, a reasonably conclusive cause was identified in only twelve. These subjects, numbered 1, 3, 8, 11, 37, 39, 44, 49, 55, 56, 58, and 62, are shown separately below. The causes marked with a '\*' (nine of the twelve subjects) are genetic disorders or have a genetic component.

Subject 1	Chromosome abnormality *	Subject 44	Meningitis at 8 years
Subject 3	Rett's Syndrome *	Subject 49	Chromosome translocation *
Subject 8	Herpes Simplex virus	Subject 55	Genetic (interbreeding) *
Subject 11	Familial encephalopathy *?	Subject 56	Down's S./Thyroid disorder (*)
Subject 37	Hypertelorism *	Subject 58	Down's S./Meningitis (*)
Subject 39	Viral infection at 11 m	Subject 62	Rett's Syndrome *

Generally, there was a much better chance of obtaining relevant information concerning cause in the younger subjects. It is worth noting, however, that the subjects in whom we can be fairly confident of attributing a cause tend to be suffering from a discrete syndrome (e.g. Rett's Syndrome) or a cause which is easily identifiable (e.g. meningitis at 8 years).

## 2.5 Medication

Dosage of all medication is shown in Figure 6.3 .

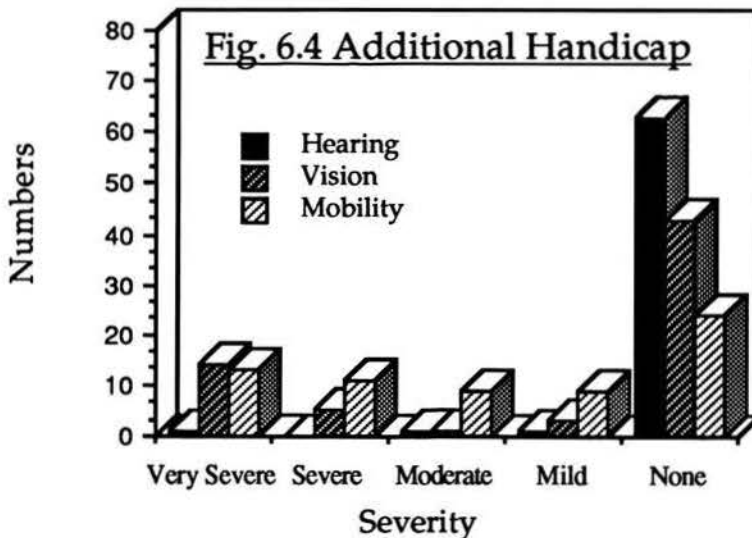


As mentioned in chapter 5, the exact dosage for anti-epileptic, phenobarbitone, benzodiazapine and psychiatric drugs was recorded for each subject and given, along with the age and weight of the subjects, to a consultant psychiatrist who produced the rating.

Anti-epileptic drugs are the most frequently prescribed, with 35 subjects receiving them in some form, and psychiatric drugs the least common, with only 5 subjects being on a (medium) dosage. It is interesting to note that 8 subjects are prescribed phenobarbitone, which has in recent years become unfashionable due to it's powerful sedative effects. The majority of these 8 are, in fact, all resident in the same institution. This may reflect the preference of their present consultant or the difficulty in changing drugs after many years of prescription. Later analysis will look for correlations between medication and behaviour.

## 2.6 Additional Handicaps

Figure 6.4 shows additional handicaps in the subjects.



24 subjects had no physical handicaps and complete mobility; 9 could walk with help (together making 50% of the sample); 9 had slightly more serious handicaps, but could crawl on their own; 11 could only move themselves while seated; and 13 were unable to move themselves at all.

Visual handicaps were slightly rarer, but still extremely common: 43 had no visual problems; 3 had minor visual handicap; 1 was partially sighted; 5 had severely limited vision; and 14 were blind.

Auditory handicap was extremely difficult to assess. Most subjects showed no or very little handicap (64), one subject was partially deaf, and one subject was suspected deaf and blind. A subject whose medical record showed that she was deaf was actually consistently able to respond to noises. Very slight deafness is now suspected, but assessment is almost impossible due to her attentional problems.

### *2.7 Other Physical Problems*

Other indicators of physical problems were recorded for all subjects. These were: degree of head control; control of visual tracking; and degree of hand control.

Most subjects had good head control (55); 6 had good control with some problems; 4 had very little control; and 1 subject had no control at all. Similarly, 41 subjects had good tracking; 3 had slight problems (usually caused by nystygmus); 4 had more serious problems; 1 had severe problems; and 17 had no visual tracking.

In hand control, 40 subjects had good hand use; 7 had slight restrictions; 7 had more serious restrictions; 9 had very poor hand use; and 3 had no control over hand use at all.

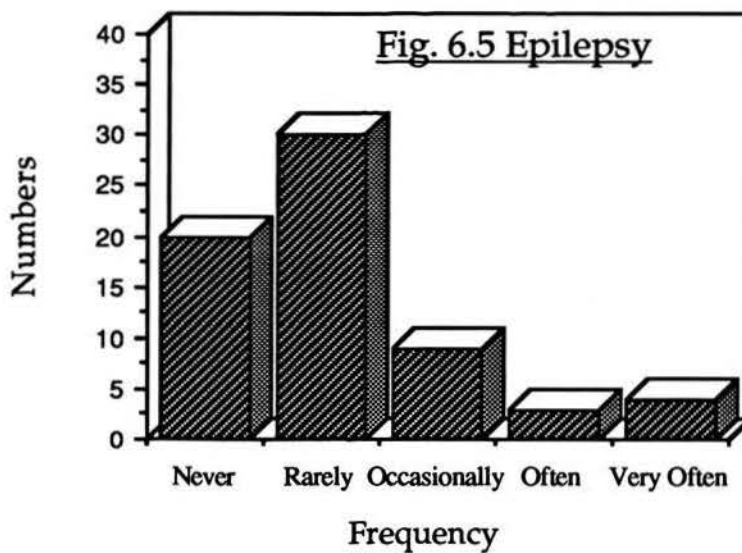


### 3. Results of the Questionnaire

These are based on the results of the second questionnaire. For each question a graph illustrates the distribution of the subjects. A comment on the results is also given, with examples taken from the first questionnaire. In many cases, a developmental framework is applied in order to help understand particular behaviours.

#### 3.1 Epilepsy

Well over half of the subjects were epileptic, and most of these had fits on average once a week. Although few subjects suffered fits very frequently, almost all of the carers considered the fits to be disturbing when they occurred.

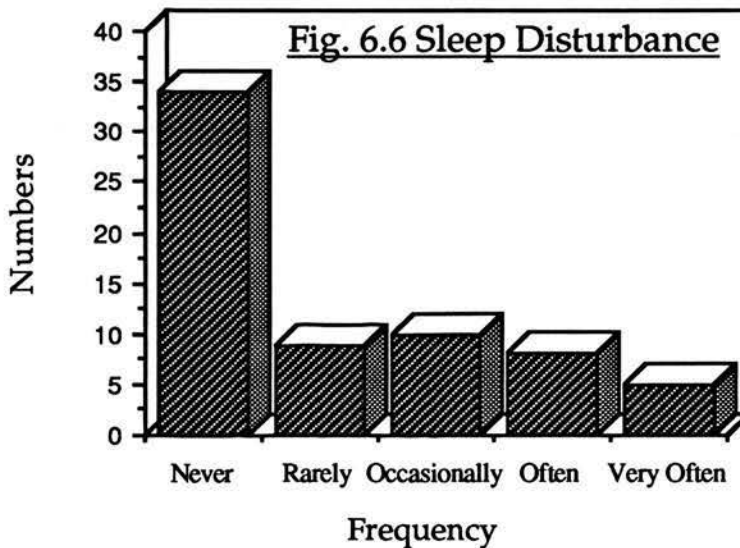


In one case, a subject had fits only rarely but these were extremely severe: after one attack he was in a coma for four days. His parents believe that the severity of his handicap increased after several of these attacks. They also described marked changes in his behaviour: after an attack when he was around ten years old, he changed from a child that enjoyed touching and cuddling his carer and sought constant affection, to actively avoiding any physical contact, though he is still capable of occasional affective responses. At the other extreme is one subject who EEG measurements have shown to suffer from epileptic attacks every thirty seconds, but does not show any sign of them in her behaviour.

All of the subjects with epilepsy were taking anti-epileptic drugs. In many cases the drugs have decreased the severity of the attacks. Two subjects had been classified as epileptic in the past but were not now considered epileptic.

### 3.2 Sleep Disturbance

Nearly half of the subjects suffered from some degree of sleep disturbance, though very few were reported to actually move about at night.

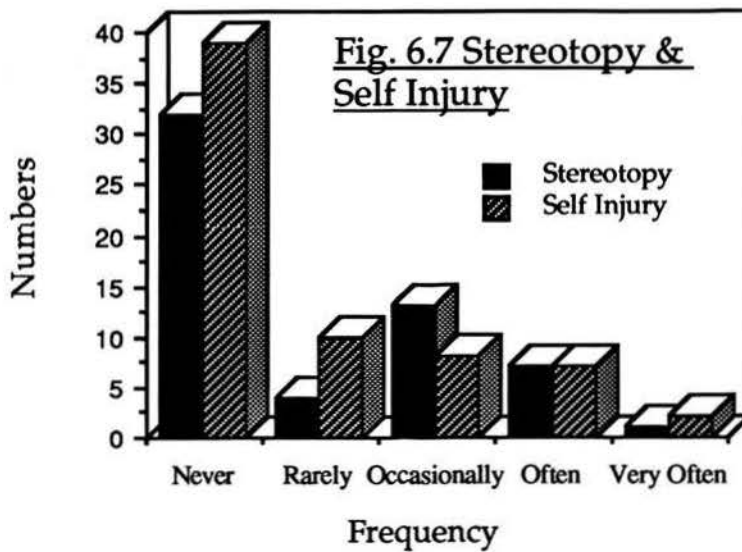


None of the subjects found it very easy to adjust to changes in the timing of routine. Two carers mentioned occasions when the subject had woken in the night and started the daily cycle from then, as one carer put it "she had her body clock knocked off". Another subject could be put to bed early by having the daily routine speeded up. One carer reported that a subject would wake up when the sun shone into his room, and would therefore wake up earlier in summer. Because of persistent problems in sleeping, some subjects were on medication to provide a regular sleep cycle. Many people with profound handicap may therefore have a malfunctioning internal body clock, though an alternative explanation for some of these events could be that physical discomfort influences sleep patterns.

One very common and very interesting finding was that many subjects would not go to sleep when they were put to bed but would spend about an hour making noises and laughing to themselves. Sometimes this was the noisiest they had been all day! The carers all thought that the subjects seemed to find this activity very enjoyable.

### 3.3 Stereotopy and Self-Injurious Behaviour

Neither self injurious behaviour or stereotopy are a common as might have been supposed, with about half never demonstrating any stereotypic movements, and a slightly larger number never showing self-injurious behaviour. Only one subject engaged in almost continuous stereotopy, and two in very frequent self-injury.

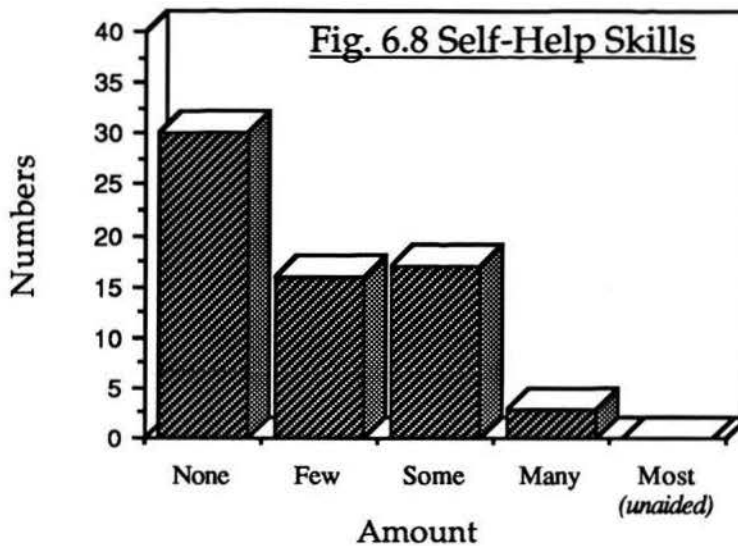


Despite the low levels of reported self-injury, one subject had permanent disfigurement (the loss of use of an eye) as a result of self hitting and at least one subjects was on medication to reduce the rate of self-injurious behaviour. Head banging and biting were both fairly common. Several subjects bit their hands or head banged when carers got too close to them. Some subjects scratched, bit or pulled the hair of carers, though in some cases the carers thought that this may have been an attempt at showing affection and establishing contact. In one case, head banging ceased altogether after the subject's teeth were removed, leading some staff to wonder whether the head banging was a response to tooth ache, though this does not explain the high frequency of head banging that occurred. Generally, some subjects seem to head bang when they are upset.

The most popular stereotopy was body rocking, though some subjects engaged in finger and hand movements. One subject was so vigorous in her rocking that she wore through the safety straps in her chair that prevented her from falling out. Some subjects rocked more when agitated.

### 3.4 Self-Help Skills

The self-help skills possessed by the subjects are shown in Figure 6.8.

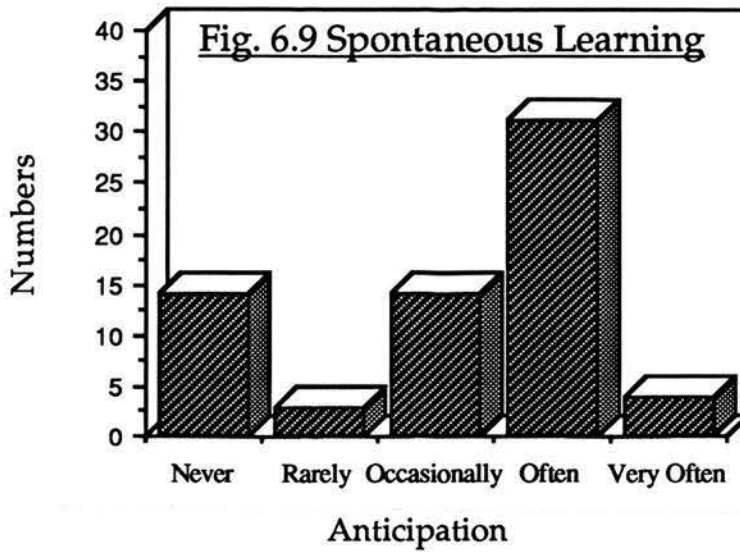


No subjects had all the skills (toileting, feeding and dressing), which is not surprising, though in some cases physical handicap poses a great problem in performing skills unaided. Nearly half of the subjects had no skills at all and were totally reliant on carers. Most, though, had some skills ranging from an ability to help put on clothes to eating food with a spoon. No subjects were able to toilet themselves.

### 3.5 Spontaneous Learning

The example used to determine the presence of spontaneous learning was anticipation of the daily routine and the results of this are shown in Figure 6.9 (over).

Carers reported that most subjects were at least aware of such events as mealtimes and the arrival of the school bus. The first questionnaire has, in fact, produced numerous interesting examples of spontaneous learning. Several subjects would become agitated if the school bus were late, especially if they were prepared for its arrival by having their coat put on, and most would be upset if it didn't arrive. In one case, the carer heard a bus and took the subject out to meet it, but it was a different bus. This resulted in very agitated behaviour from the subject.



Many subjects would become agitated if meals were late. Several carers reported that this agitation would vanish if the carers entered the kitchen to prepare the food. Food being an important part of life, many people with profound handicap show remarkable learning ability when it comes to anything connected with it. One institutionalized subject knew where the biscuits were kept in the staff room and if he noticed that the door to the room had been left unlocked, would run in and head straight to the drawer where they were hidden. Many subjects would stand by the kitchen door if they were hungry. One subject would steal sandwiches from the kitchen but would wait until he knew they had been made. Another subject had a tremendous liking for tea and would wait in the kitchen when visitors arrived because she knew they would be getting a cup. One subject loves H.P. sauce, and refuses to eat meals until she sees her mother reach for the bottle. She can be fooled, however, if her mum only pretends to pour it! At least one subject had learnt never to steal food while it was cooking, because it was too hot.

Many of the subjects recognized where they lived from a car. One would become agitated if the car they were in passed the hostel where they would stay for respite care. Another refused to leave the car when arriving in the driveway of such a hostel for another stay. Two carers reported that subjects would screw up their faces when they saw a face flannel in the morning, ready to be washed. Many subjects have recognized (and got very excited about) a once favourite piece of music. In one case the music was a television theme tune and was recognized after a gap of many years.

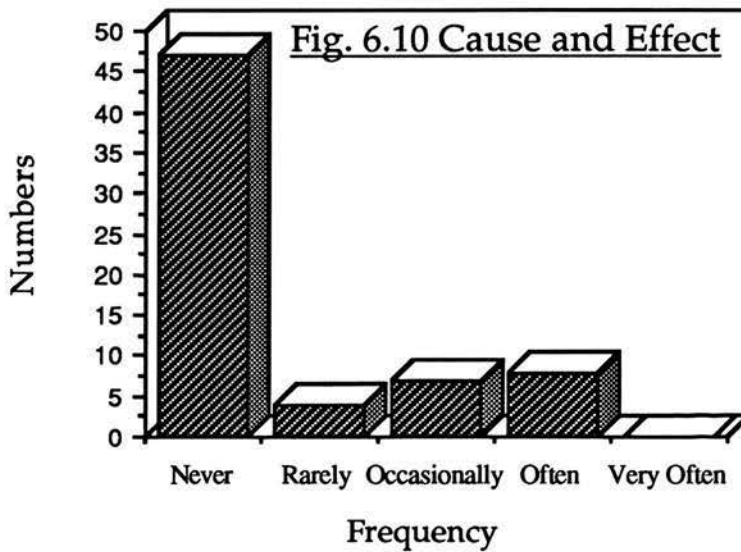


Sometimes the learning can be very rapid. One subject learnt to expect whatever additions were added to his regular meal, even if they were presented only once: "give him a yoghurt one day and he'll expect it the next day or he'll have a temper tantrum".

All of the carers were sure the subjects knew their own names. They were also sure that they recognized their regular carers, and in the hospitals some felt that they would deliberately behave badly if there was a new carer on duty. One institutionalized subject, his carer was sure, would only tease those other residents whom he knew would not hit back. Some carers believed that the subjects understood many words, but during this research only a few showed any understanding, and these were of simple, habitual requests (such as 'take this tumbler').

### 3.6 Knowledge of Cause and Effect

As can be seen in Figure 6.10, very few subjects consistently demonstrated this.



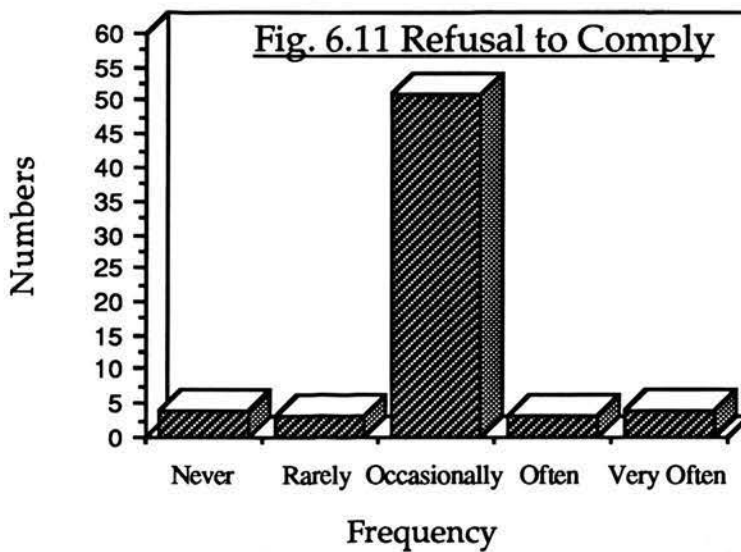
There is, of course, the possibility that some subjects were capable of doing so but did not, but carers could usually be quite certain. The example used was whether the subjects could press a switch on a musical toy to obtain sounds. Most carers did not think that their charges would do this. Again, though, physical problems may prevent the demonstration.

Some subjects play with such toys and do operate them successfully. Some can

also wind them up. Three subjects regularly attempt to turn the television on. One subject demonstrates that he knows cause and effect by continually flushing the toilet, which he enjoys very much. Interestingly, some subjects show no knowledge of cause and effect using toys or machines, but do seem to attempt to influence carers to produce a desired action.

### 3.7 Refusal to Comply with Carer

As can be seen from Figure 6.11, most subjects refused to do as their carer wished occasionally.

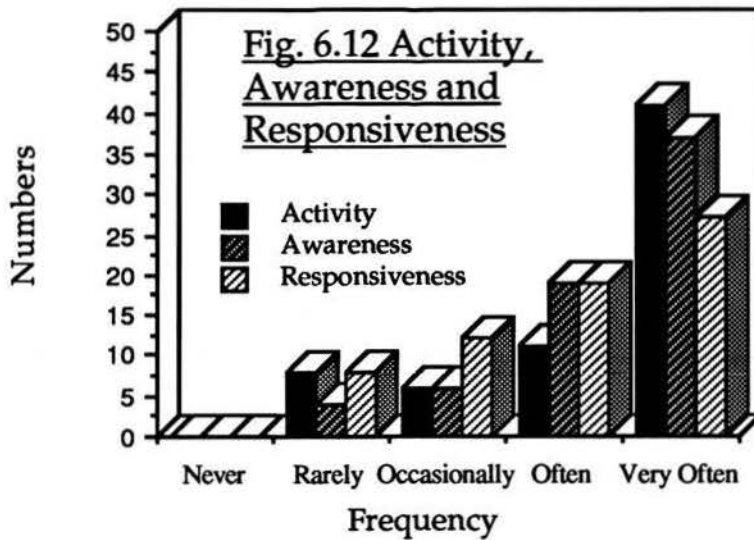


In most subjects, non-compliance involved little more than refusing to eat a spoonful of food. As this behaviour demonstrates a degree of independent thinking it is not necessarily a bad thing, and many subjects demonstrated it from time to time. Often, non-compliance is related to a mood or to events that have happened during the day. In one instance, the parents believed that a refusal to eat dinner was a reaction to the father being absent from home for five days.

In some subjects, however, refusals are much more frequent and this behaviour has developed into a serious hindrance to care. In these cases this has usually been labeled as 'behaviour problems'.

### 3.8 Activity, Awareness and Responsiveness

The frequency of periods of activity, awareness and responsiveness in the subjects is given in Figure 6.12.



All subjects were considered active to some degree on some occasions. The majority were thought by their carers to be active most of the time, but there were some exceptions. One subject did very little, and would never assist if he was being moved, for example. Physical limitations meant that some subjects could move around freely during periods of activity whilst others were confined to small movements in a chair, but this was taken into account in the rating.

Similarly, all subjects were considered aware of events around them to some degree. Some were thought to be aware during their entire waking hours, but this is of course very hard to verify. Many certainly appeared to be aware during the entire length of my visits. Some subjects did not seem to be aware at first, but later showed signs that they were actually attending by reacting to events or orienting immediately after. Some had sensory handicaps which made it difficult for them to be fully aware, and for us to tell when they were in contact with environmental events. Interestingly, some subjects demonstrated a particular awareness of events going on around them. One subject, for example, spends much time looking out of a window onto the street at the people passing.

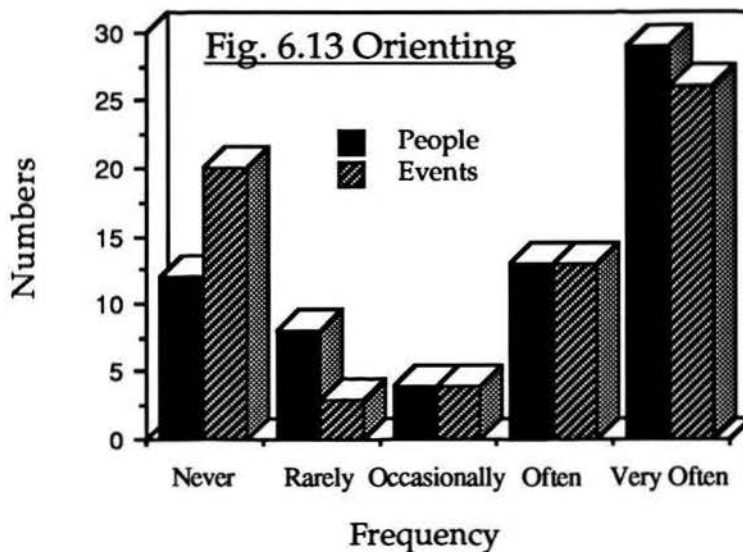
All subjects were considered responsive. This received some confirmation from observation and the video analysis. It was notable that some subjects were especially

responsive on receiving attention from their carer, and would change their behaviour completely. One subject seemed asleep until her carer started to talk to her.

Generally, the level of responsiveness depended on the mood the subject was in. Often, the same approach by the carer can have a completely different reaction from the subject, depending on the mood of the subject. One subject, for example, will usually respond positively to an approach by his carer, and will display signs of enjoyment at play involving physical contact. In some moods, however, any approach - and especially any physical contact - meets with violent rejection. Similarly, another subject will typically respond to approaches by a carer with high levels of positive behaviour, but when in a bad or a 'reserved' mood, will not respond to anything at all. In fact, in one subject such unresponsive behaviour is the more typical, with positive responses to carers only being seen during very rare good moods. The reason for these changes in moods is discussed later.

### 3.9 Orienting to People and Events

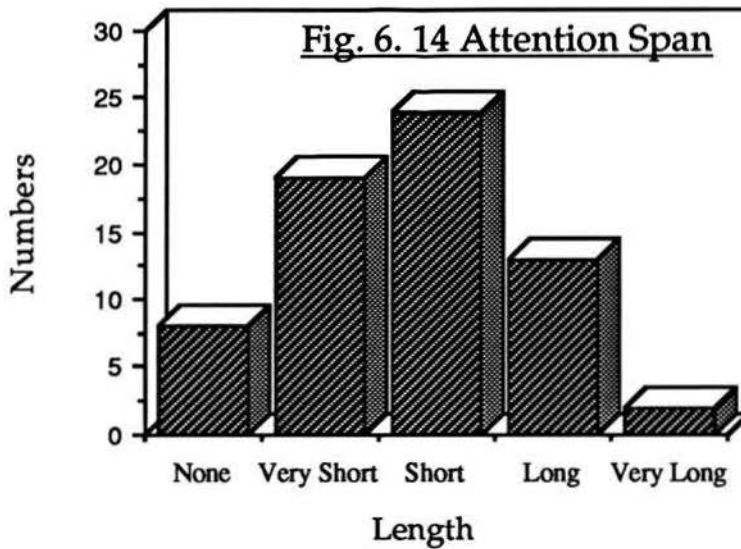
Orienting behaviours of the subjects are shown below.



Most subjects are sufficiently interested in a person entering a room, or an event occurring nearby, to turn to them. Presence of a visual handicap may account for many of the subjects recorded as non-orienting, though it is possible that they do orient using hearing and thus do not turn to face directly. Carers may find this much more difficult to identify as orienting.

### 3.10 Attention Span

Attention spans of subjects are given in Figure 6.14. The 'short' attention span in this figure represents 30 seconds. Overall, very few subjects were able to attend for a longer length of time, but if motivated by something particularly interesting - typically food - the attention span was often considerably longer. Much depends on the mood of the subject at the time, the identity of the carer (familiar carers will typically attract more attention), and what the carer is trying to get the subject to attend to.



### 3.11 Interest in Objects and Tendency to put Objects in Mouth

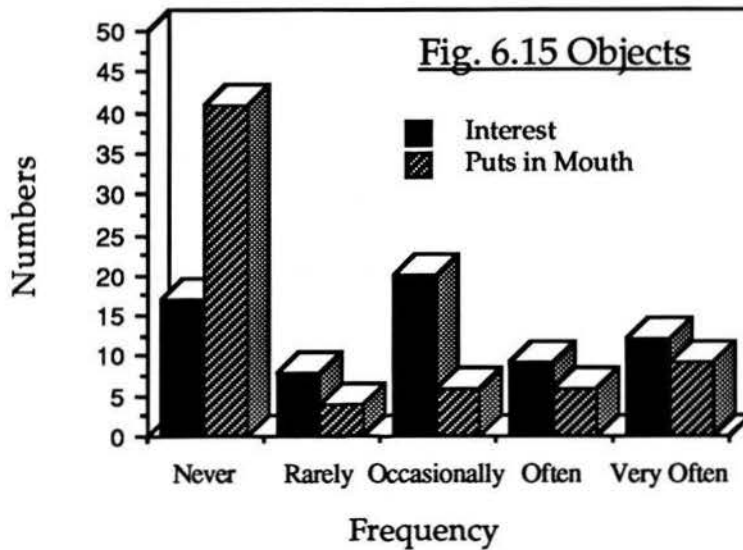
Many of the subjects showed some degree of interest in objects. In two cases, this was an intense, stereotypic, compulsive interest. Comparatively few subjects placed objects in their mouths.

Two subjects were obsessed with objects, and played with them for the duration of both visits. In one case they were a pencil and toy car, in the other they were an assorted collection of toys and empty tins which the subject kept behind the sofa. This subject knew if any of these were missing, and would search until he found it. In both cases objects were continually turned over in the hands.

Two other subjects showed an autistic tendency (a dislike of change and



obsessive performance of routines) in their behaviour towards objects. If anything had been moved whilst they were away from home, when they returned they moved it back to its original position. In one case this involved the ornaments in the front room, curtains throughout the house (which had to be drawn), and her bed (which had to be tidy). In the other, it involved the position of the table and sofa.



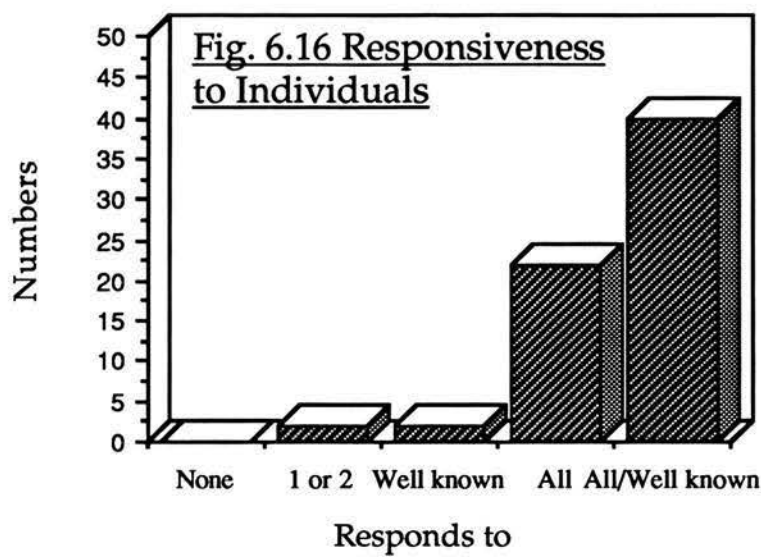
The objects which attracted the most interest were toys: soft toys, squeaky toys, dolls and, especially, musical toys. Objects and toys were rarely played with appropriately, though a few subjects could operate a musical toy by pressing a button, and two could wind it up.

Several subjects enjoyed playing with lengths of string or cotton, or bits of paper, which they twirled in their hands, and occasionally ate. Two subjects were obsessed with the family washing machine, and would sit and stare at it for hours while it was working. Another subject liked the food mixer, so the attraction in these cases may be the vibration. Two other subjects, however, were scared of the sudden noises made by some objects (such as a vacuum cleaner).

The mouthing of objects is typical of Piaget's second stage (1-4 months) and was perhaps to be expected to occur much more frequently in people with profound handicap. However, over half of the subjects were reported never to mouth objects at all.

3.12 Responsiveness to Individuals

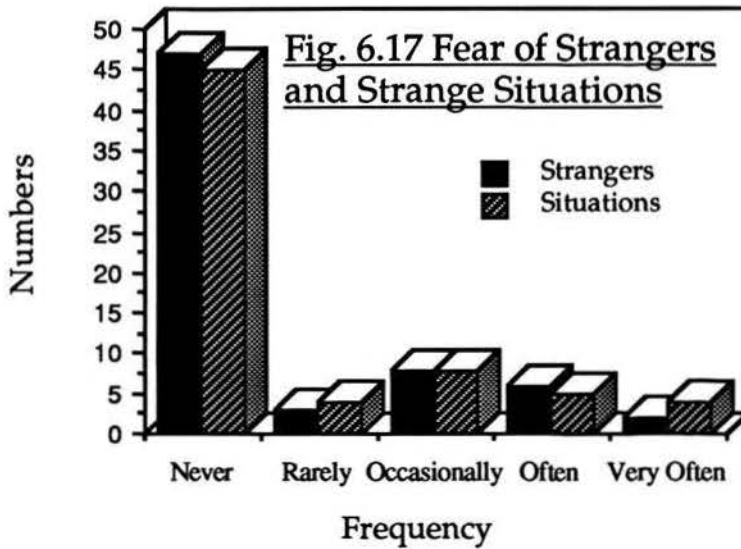
The responsiveness of subjects to different individuals - the people that each subject is likely to respond to - was looked at for indications of the nature of the relationship or attachment with the carer.



All subjects responded to some people. The majority responded to all people, but especially well to a few well-known people, an indication of balanced attachment behaviour. Usually the people that were responded to especially well were one of the primary carers, and occasionally someone not seen so often, such as a grandparent, or in the case of one institutionalized subject, her real mother. A minority of subjects would respond *only* to people who were well-known, in some cases one or two individuals. These subjects appear to be extremely overdependent on the carer, and this may indicate a disorganized and insecure attachment. These findings are discussed in greater detail in the next chapter.

### 3.13 Fear of Strangers or a Strange Situation

Fear of strangers and of a strange situation were investigated because they are important indicators of the nature of the relationship between subject and carer. If a subject shows excessive fear of strange people or a strange place, this suggests that they are extremely dependant on a primary carer. If the subject shows no fear at all, this suggests that there is no strong attachment to a carer. A balanced attachment may be suggested by a clear preference for a primary caregiver, especially when in need of comfort or support, but a willingness to explore new environments.



Fear of strangers (typical of all infants from 1-4 months and heightened from 8-12 months) was not reported very often, though some do show it. Usually this manifested itself as a general quietness and two subjects did this very frequently. Two carers revealed that until recently subjects did show a heightened fear of strangers and abnormally strong attachment (which was manifested in a desire to keep the carer in sight at all times). Many, however, showed no such fear and would happily play - or walk off with - anyone. Some showed a strong liking for people with glasses, others a fascination for beards, and many a liking for small children which seemed to override the fact that they were strangers. On rare occasions some subjects took a dislike to someone. Carers did not know why, but in one case the carer believes it was purely based on physical appearance (the person was tall and had long black hair, which the carer believes could have been alarming).

Fear of a Strange Situation was not very common, but present in some subjects. One subject was very afraid of strange places, particularly if they were noisy. Examples cited by her carer included churches and supermarkets. Most of the subjects, in hospitals and at home, seemed to behave differently on holidays, and enjoyed the experience. Most subjects certainly seemed to notice the difference between places, and of the home subjects nearly all of the carers mentioned that they thought that the subject did more at school. Several told how the subject was quieter at a new school at first, but gradually adjusted to it.

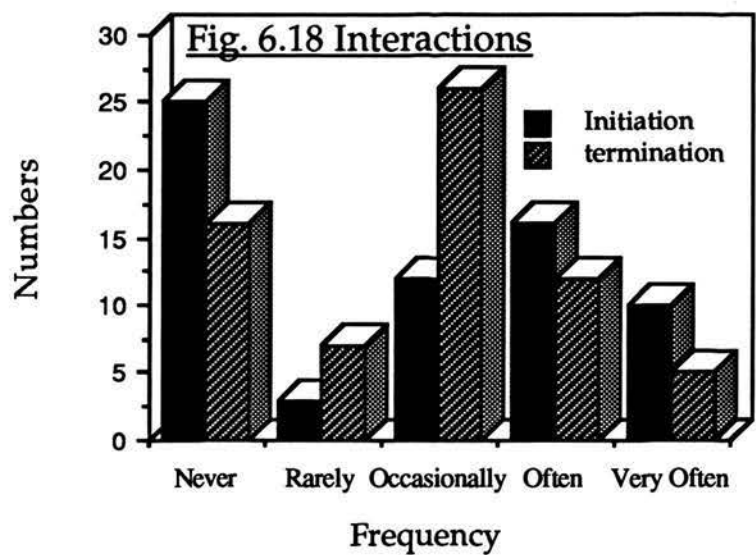
Interestingly, four mothers separately mentioned traveling to school to see their children and being completely ignored by them, which is not the usual reaction at all. Similarly, several parents who had placed their child in temporary respite care for a week told how the children had avoided interactions for some time after returning home. This behaviour at first appears to be something of a mystery, but may actually be important evidence that attachment between children with profound handicap and their mothers has occurred.

Generally, indications of attachment were much more frequent in those subjects living at home. This is not surprising: staff in hospitals are rarely based on one ward for periods longer than one or two years, which means that any attachments formed with residents are continually disrupted. These results are discussed in greater detail in the next chapter.

### *3.14 Initiation and Termination of an Interaction*

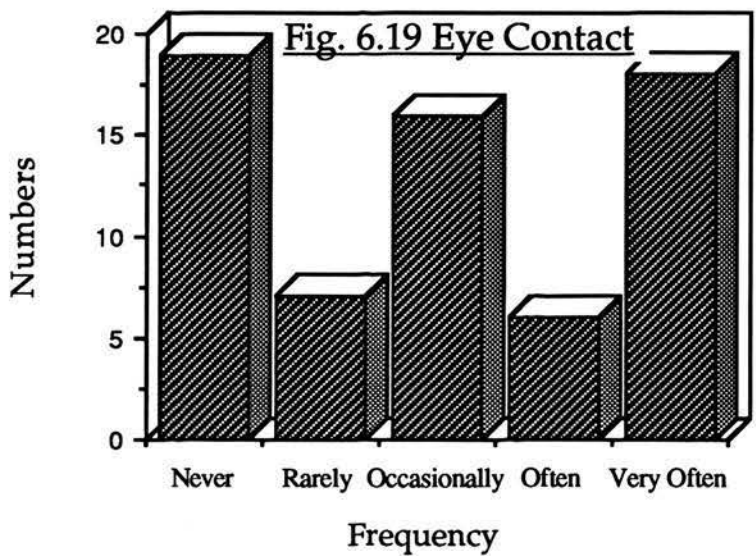
Deliberate termination of interactions by the subjects was reported as being fairly common, which is not unusual considering the short attention span. Most ended or avoided an interaction at least occasionally. Carers typically reported that much depended on the mood of the subject at the time. Initiation was also reasonably common, though there were large individual differences. There was not a great deal of evidence of initiation in the sessions.

The frequency that subjects were considered by carers to initiate and terminate an interaction is given in Figure 6.18 (below).



3.15 Eye Contact

This was reported to be much more frequent than expected.



The frequency rate appears very high, especially when the visually handicapped subjects are taken into account. Subjects certainly do seem to be capable of eye contact, but it is unclear whether they do offer quite as much as this result indicates, or

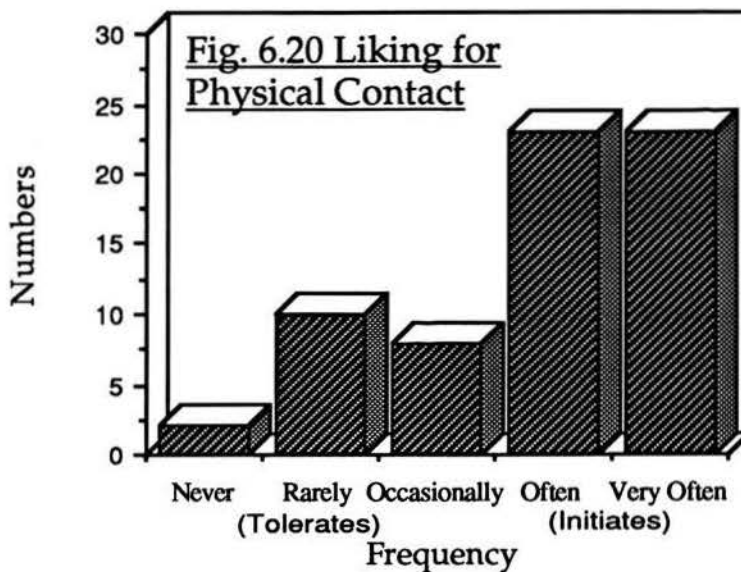


whether carers assume that they do, eye contact playing such a major part in normal interaction that they may assume that it is there.

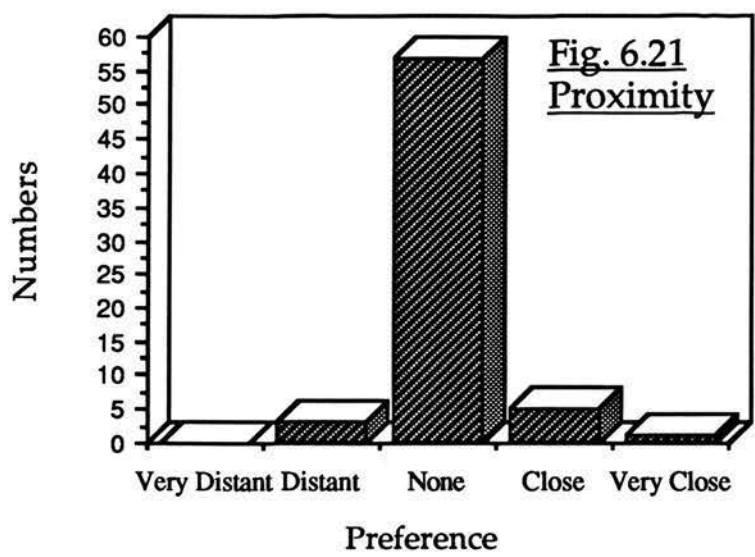
Some subjects (particularly those with Rett's Syndrome, of which good eye contact is a characteristic (Kerr, 1986)) certainly do give sustained eye contact. In another case, though, the carer stated that the eye contact given by a subject was more of a stare, which felt quite unsettling.

### 3.16 Liking for Physical Contact and Proximity

Most subjects enjoyed physical contact, as can be seen from Figure 6.20.,but again this depends upon mood.



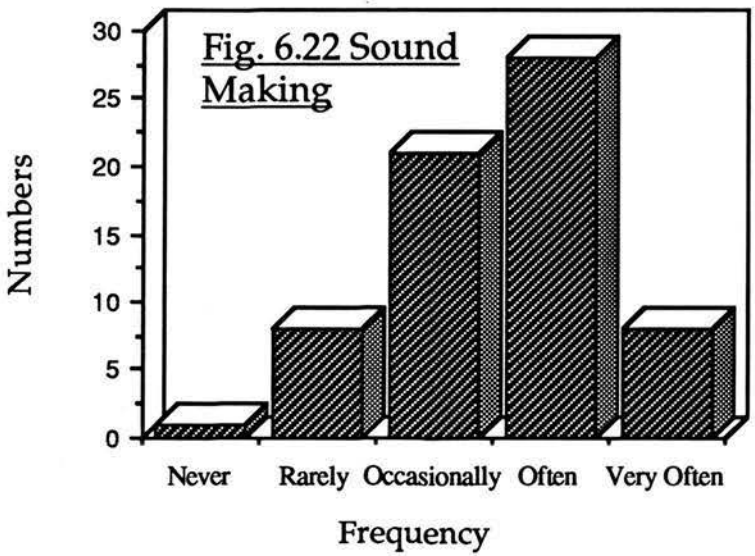
Several did not like to be touched by carers and would scratch them if this were attempted, but would allow it if they were in a good mood. One subject would only allow it during recovery from an epileptic fit. Another subject only allowed staff to touch him when they were visiting him on a medical ward where he had undergone surgery. A few subjects invariably reacted adversely to physical contact. Given the amount of physical care - toileting, washing etc. - that all people with profound handicap are subjected to, it is perhaps not surprising that a minority build up a resentment to being handled. The majority of subjects, however, do allow physical contact, and many will initiate it with a cuddle.



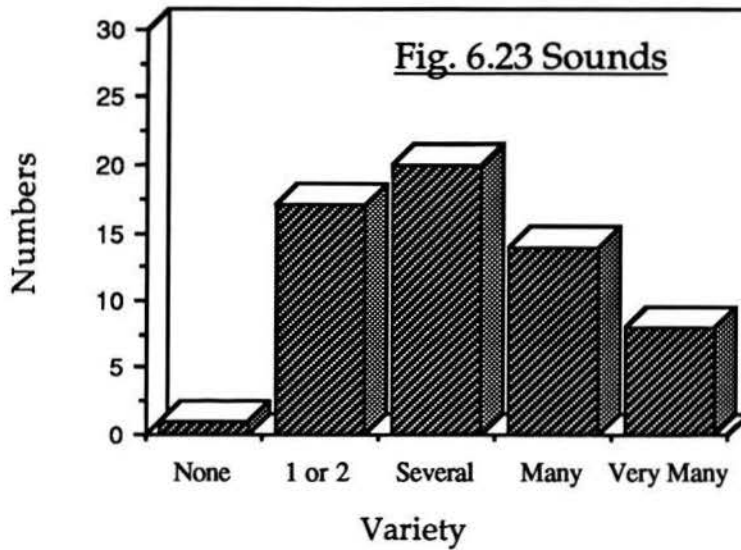
Most subjects showed no consistent preference (or were physically unable to show preference) for proximity to carers, apart from those mentioned above who resented contact, and two other subjects who relished it. Of these last two, one spent her time walking around a ward and would take hold of people if they were close to accompany her. The other enjoyed cuddling with her carers and would if allowed would spend all day in very close physical contact.

3.17 Sounds

Most subjects made sounds fairly regularly, as can be seen below.



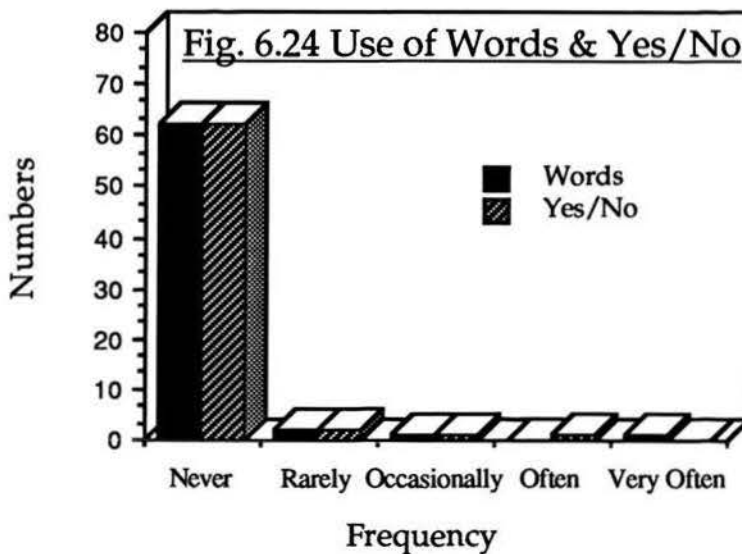
A very few subjects make no sounds at all, though it is possible that they may make them on very rare occasions. In contrast, some subjects repeat sounds continuously, and in these cases it appears to have become a stereotypic behaviour.



Many used a variety of sounds, and these tended to be basic and monosyllabic. Some repeated one sound. Few made any noises approaching vocalizations.

### *3.18 Use of (Inappropriate) Words and Yes/No*

Frequency of use of words (in all cases inappropriately) and yes or no (vocal or non-vocal) are given below.

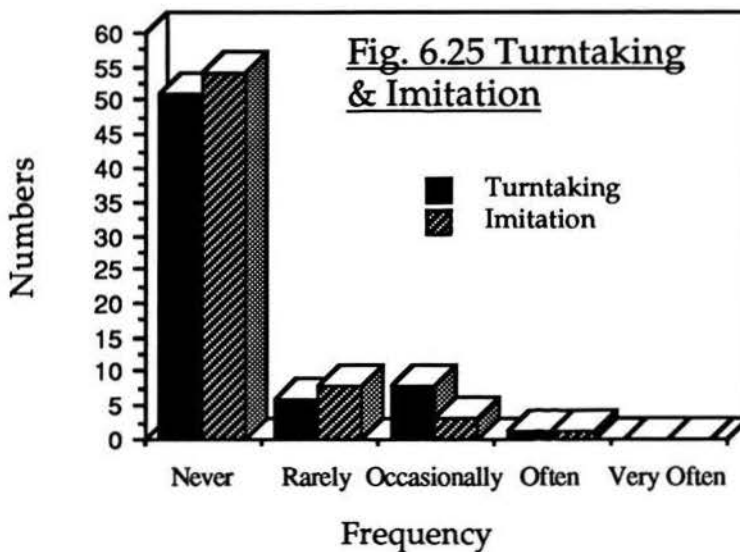


A vast majority used no words. Four subjects did speak, but none consistently used any words appropriate to the context, other than by repeating words spoken by the carer. Of these subjects, three could approximate one or two words, and another, who was extremely echolaic, could say many.

Only three subjects were reported to be able to use 'yes' or 'no', in two cases by signing, and in one case by speech (actually an approximation of 'aye' and 'nay'). In all cases they are not used consistently, and are often difficult to interpret.

### 3.19 Turntaking and Imitative Behaviours

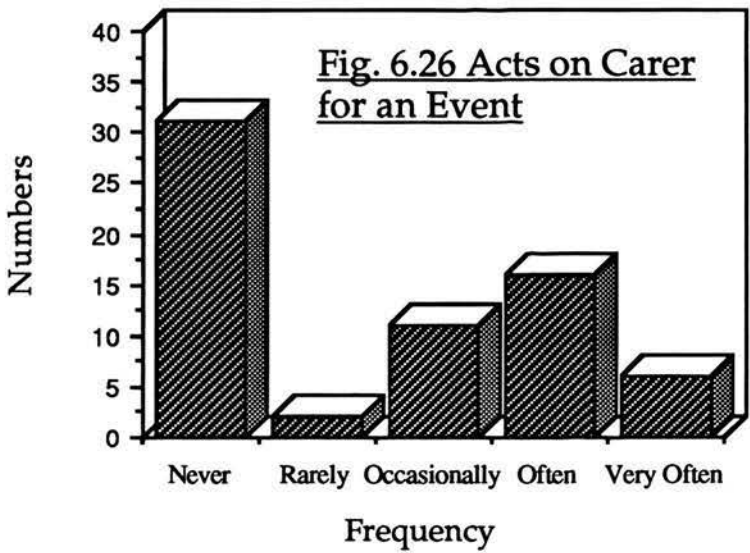
Turntaking in the subjects - the conversation-like interjection of sounds in gaps in the carers speech - is very hard to verify. Fifteen carers reported its occurrence, though none thought it very common. It is possible that they are mistaken, or reporting chance events. In at least one case, however, turntaking did seem to be occurring during a session, though it is very difficult to decide if it should be ascribed to skill on the subject or the carers part.



Imitation is another category which carers thought to be very uncommon, but present in a minority. It, too, is very hard to verify. In three cases, however, the imitation was of speech, and this occurred during sessions and was easily noticed.

3.20 Acts on Carer for Event

The frequency of acting upon a carer to produce a desired event is shown below.



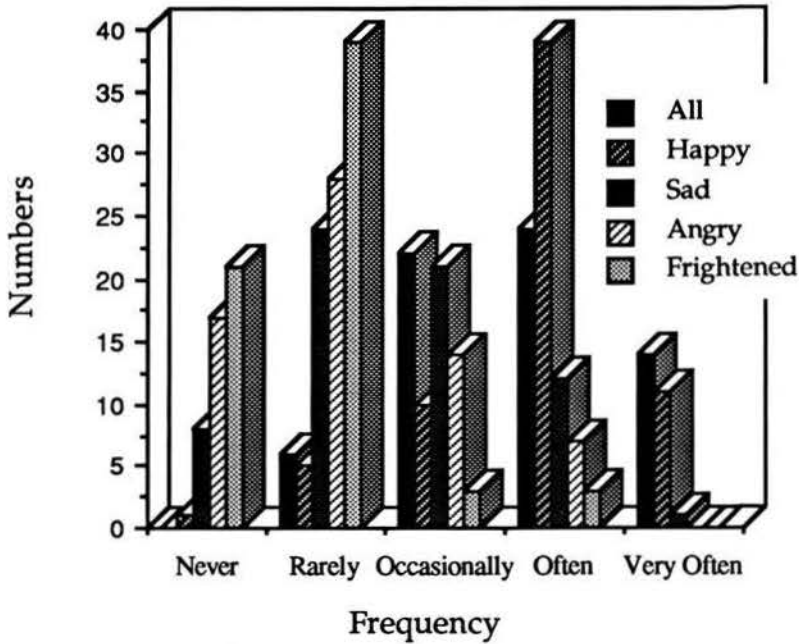
Few subjects consistently acted on carers to obtain events, but a substantial number did demonstrate this ability occasionally. In most cases, this involved pointing to a desired object or taking the hand of a carer and directing them to it. Sometimes a subject would merely pull the arm of a carer to get their attention. One subject actually pushes carers hands onto a switch on the television to get them to turn it on. Several subjects direct the carer to perform a play behaviour which they enjoy. One subject lowers his head and pushes the carers hand onto it, to be stroked. A blind subject will clap with his own hands unless a carer is nearby, when he will reach for their hands and force them together to initiate a clap. Another subjects will simply push out his tongue during play to get the carer to stroke it.



### 3.21 Facial Expression

Display of facial expression was very common in the subjects. This was also observed during my visits. Of the types of facial expression, a happy expression was reported the most frequently seen, whilst a frightened expression was very uncommon (in most cases the subjects would be protected from exposure to events which are likely to be perceived as frightening).

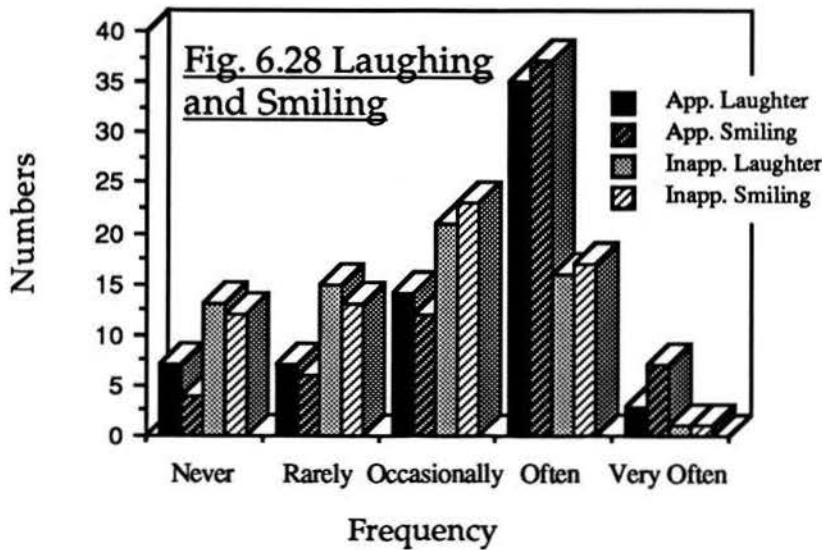
**Fig. 6.27 Facial Expression**



Carers would seem to have responded honestly to these questions, some reporting a high occurrence of sad expressions in the subjects. Facial expression, of course, depends on the mood of the subjects, and also on their level of arousal. Many subjects may go through one or many days without giving any responses or making any expressions.

### 3.22 Appropriate and Inappropriate Laughter and Smiling

The majority of subjects were reported to often demonstrate appropriate smiling and laughter (reactive and responsive to preceding events and the actions of the carer), which is confirmed by my own observations during visits.

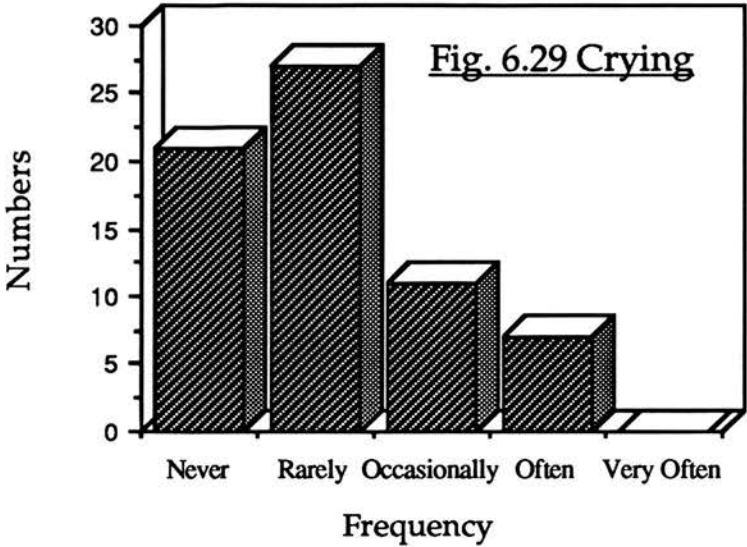


Inappropriate laughing or smiling (unrelated to any preceding event) is fairly common in many subjects. Sometimes it is very hard to define to carers, who may consider that, even if there is no obvious precursor to the subject laughing to himself, "he must be thinking of something funny". Such behaviour is here classed as inappropriate. Some subjects laugh quite a lot when they are in bed, and carers note that they often seem to laugh in their sleep. Some carers believe that inappropriate laughter is related to anti-epileptic medication.

### 3.23 Crying

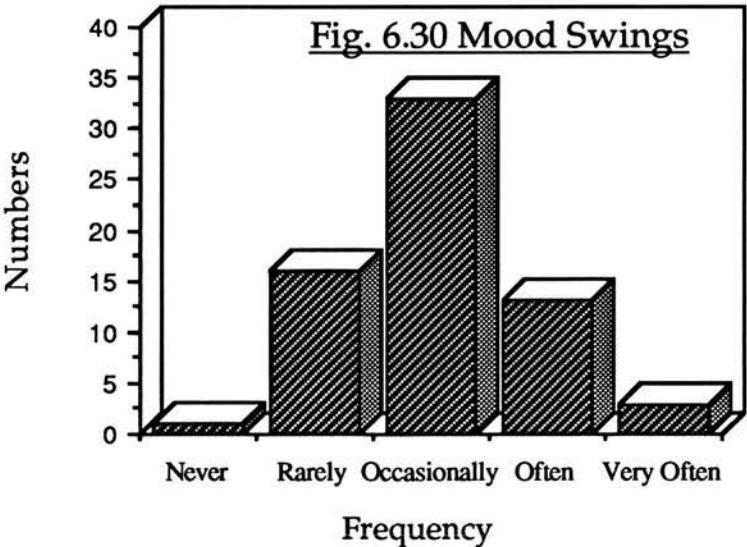
Crying is not very common (see figure 6.29, over). One subject had cried only once, over thirty years ago. Many subjects were reported not to have cried after having accidents and being in considerable pain: in one case a subject picked up a boiling hot teapot and showed no ill effects. In another, a subject scalded herself very badly, and on another occasion broke her leg. Both times her parents didn't realize anything was wrong at first, because she did not complain. The doctor who treated her in casualty was amazed. Many subjects, however, certainly do feel pain (one subject, as was

mentioned earlier, learning not to touch food that is cooking by burning his fingers slightly).



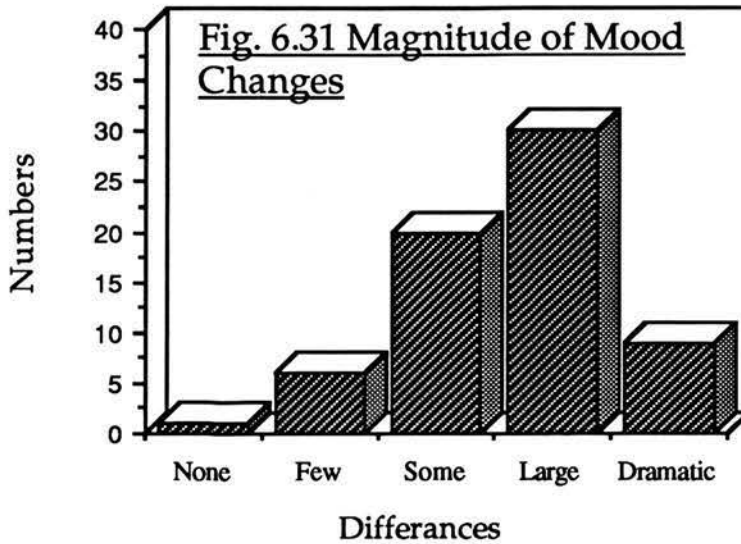
3.24 Mood Changes

Mood changes were detected in all subjects except for one, who has additional sensory handicaps and who seemed to remain the same for most of the time.



Mostly, the mood changes affected a variety of behaviours but were not too great. Three subjects experienced very frequent, very serious mood changes,

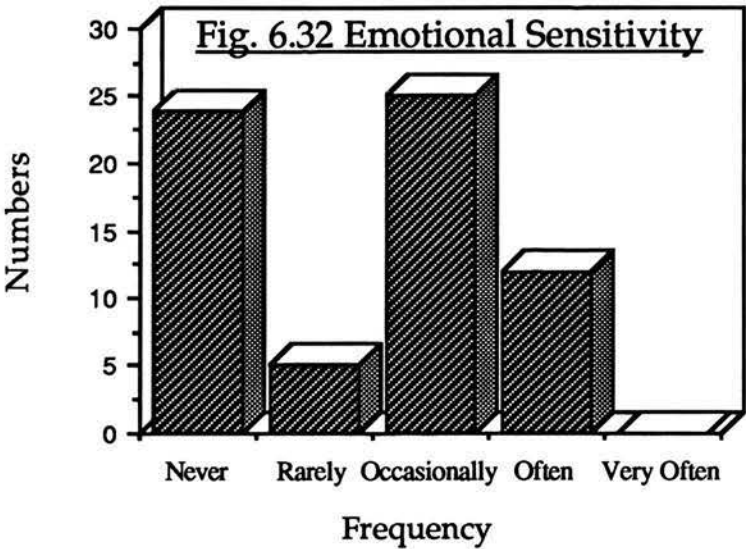
however. In one case they were completely unpredictable and could change every few minutes. In bad moods this subject could become extremely violent, and slept on his own because of the threat he posed to other residents. Another subject was suspected of having a depressive illness: One session took place in a period of depression and the subject cried throughout, the second during a non-depressive stage where the subject's behaviour was completely different. In all of these cases the causes of mood swings were completely unknown.



Most subjects experienced occasional, slight mood changes which the carers reported no difficulty in interpreting. Usually, changes in mood could be traced to a cause such as physical illness or injury, constipation, boredom during school holidays, a new carer, or being forced to do something. Often, a bad mood could be changed by the use of soothing speech by the carer. Sometimes a mood changes after a short sleep. Carers thought that most subjects made different noises according to their moods. Several subjects had occasional temper tantrums involving screaming and kicking out at carers, which contrasted strongly with the affectionate behaviours in their repertoire, such as cuddling their carer.

3.25 Emotional Sensitivity

Carers reports of the subjects 'picking up' the mood of the carer are hard to verify but quite common. Instances cited include a change in behaviour in one subject after the carer suffered a bereavement. Several subjects seem to become agitated if their carers have arguments. It does seem possible, at least, that the subjects are sensitive to changes in the carers behaviour caused by emotional upsets. Interestingly, the head teacher of a special school reported that it was possible to guess when something had happened at a child's home by the change in their behaviour.

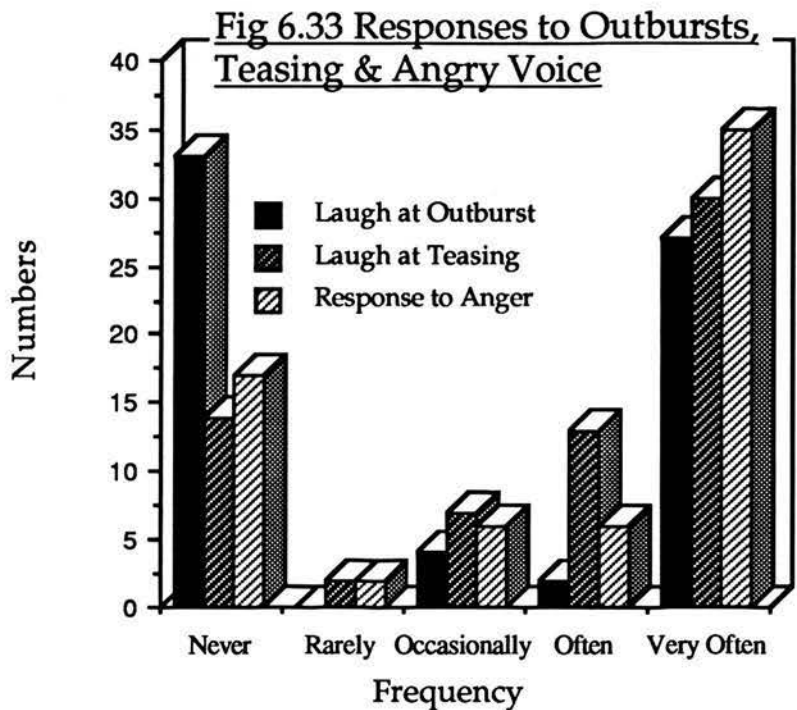


Generally, carers thought that most subjects would be sensitive to a party or a happy atmosphere (many subjects became much more sociable in such situations) but were unsure about sensitivity to a more subtle, sad atmosphere.



3.26 Laughter at Emotional Outburst in Others and at Teasing by Carer, and Responses to an Angry Voice

Frequencies of these behaviours are given below.



As mentioned earlier, many subjects demonstrate appropriate laughter. In addition, half of the subjects show a specific predisposition to laugh at certain events. This was revealed in the first questionnaire when carer after carer would begin to answer a question on humour with "he's got a peculiar sense of humour". They revealed that the subjects typically laughed at the carer dropping something, tripping up, hurting themselves, getting angry with themselves, or telling off someone (usually a sibling). There are a great many examples: one subject was "playing with the neighbours little girl. When she fell over he laughed!"; another laughs "if you drop something and shout 'oh no!'". Many will laugh more if a particular person drops things or trips up (their brother, for example). Four carers firmly believed that the subjects would deliberately stretch out their legs in order to trip people up. One of these is completely blind.

These things, then, can provoke a great deal of laughter, and at first the idea of laughing at someone else's misfortune seems perverse. It is very often and very

exactly reported, however. I think that the most likely explanation is that the subjects are responding to an uncharacteristic and unexpected change in the carers tone of voice - the emotional outburst. A question on this in the second questionnaire revealed that half of the subjects show this characteristic.

This conclusion receives support from other events reported by carers. Two subjects, for example, show an uncanny ability to laugh at the punchlines of jokes. Their carers do not believe that they can understand them, but that somehow they must pick up cues from the joketeller. Similarly, one carer tell of how her son was "entranced when his sister started to read Shakespeare out loud to practice for the school play".

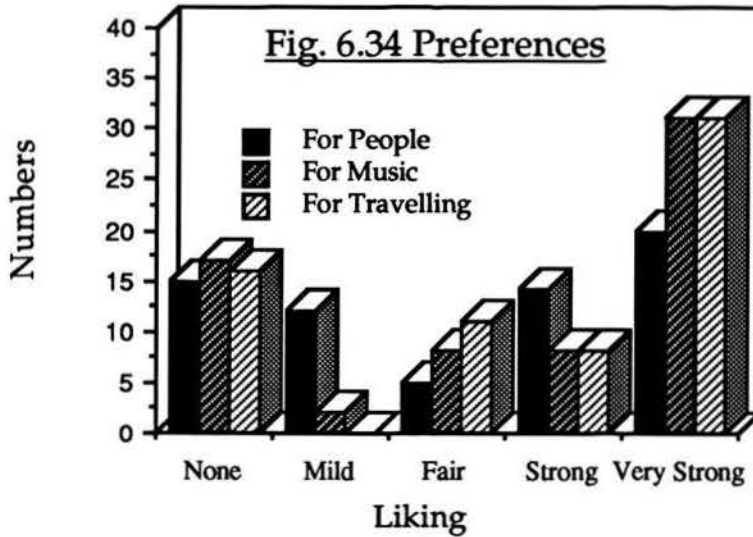
Other things which prompt laughter may also be related. This includes laughing at teasing by a carer, which sometimes itself involves mock 'telling off' tones. Other carers specifically mention that subjects laugh at funny voices being put on by the carer. Sneezes also cause great mirth, though normally not so much the sneeze itself, as the intake of breath and surprise which precedes and follows it. Some laugh at 'slapstick' comedy on the television. One subject laughed while watching football on television.

This 'laughter at emotional outbursts' may be an important observation and I will return to it later in this thesis.

Response to the angry voice of a carer is also related to the laughter at emotional outburst in that it implies a sensitivity to tone of voice. In fact, carers thought that the majority of subjects react appropriately if a carer raises their voice, and that they will stop whatever they were doing at the time, although some subjects are merely startled by the noise and then continue. Others, however, will laugh, and carers were convinced that many subjects will tease them deliberately.

### 3.27 Expresses Liking for People, Music and Traveling

The majority of subjects showed a variety of preferences, some being held quite strongly. Carers thought that most subjects expressed strong likings for people and liked to be around them, though there was a minority that did not.



Most subjects expressed a strong liking for music. In several it was a very notable characteristic, and changes in behaviour and mood would occur if music was turned on. Many subjects had favourite types of music. Usually this consisted of any pop music, though some liked only slow music, some liked country and western, and others Scottish country dancing. One subject - to the mystification of his parents - showed an extremely strong liking for old Frank Sinatra records. He is actually very selective about the music he listens to, and will not tolerate recordings made by Frank Sinatra when he was older, getting agitated if his parents play them. It is worth noting that this subject is also one of the most handicapped. Several subjects had favourite television theme tunes, and would literally drop whatever they were doing if they heard it. One or two subjects would try and get the carer to put on music for them by looking towards the record player. Many subjects show a dramatic change in behaviour when music is played. Some become much quieter, some start to laugh, and others begin to move about or dance in time with it. In an extraordinary change in behaviour, one blind, extremely handicapped subject becomes attentive when an electronic keyboard is introduced in play. Sometimes the carer taps five times in a simple beat, and the subject will add the last two taps himself.

The reasons why some pieces of music are preferred over others is not clear. A

possibility, however, is that the favoured kinds of music echo the preference of infants for the characteristics of prosody in motherese (i.e. simple, repetitive and high pitched), discussed earlier in Chapter 4.

Most subjects expressed a liking for traveling, mostly in cars and buses, though some also enjoyed train rides. In some it was quite excessive, and four carers mentioned that the subjects become very agitated if the car stops (for example at traffic lights), some having a tantrum and crying or head banging until it starts to move again. It is hard to identify the appeal. Some seem to enjoy the view from windows, but as some blind subjects enjoy traveling this cannot be the only explanation. I would guess that the proprioceptive experience is the important one. This is reinforced by the carers frequent report that the subjects also enjoy water activities and hydrotherapy.

### *3.28 Some Observations on the Subjects*

This questionnaire has revealed a fascinating variety of behaviours in people with profound handicap. Although there were a great deal of individual differences, some patterns of behaviour have started to emerge.

Amongst the interesting findings were that several subjects demonstrated autistic behaviours. This ranged from a tendency to withdraw from people and antagonism to being touched, to one subject who was obsessed with the positions of most of the objects in her house. There is a major diagnostic problem with respect to autism in people functioning at such a low intellectual level, but low incidence in people with profound handicap is suspected.

An encouraging finding to emerge from these results was that many carers reported that the subjects had changed a great deal in recent years, almost exclusively for the better. Usually this had involved a growing awareness in the surroundings and an interest in other people. Some subjects had changed from being violently opposed to physical contact to actually seeking it. Others had once spent their time lying motionless and ignoring their carers, showing no facial expression, but were now much more outgoing and sociable. Some had gradually stopped screaming, head banging, and other maladaptive behaviours. Carers often attribute such changes to maturity, and on occasions to an improvement in care: although most subjects who had improved were children, some were much older. In one case the carers thought that a 'music and movement' programme had contributed most to the changes.

A final comment is that the results clearly demonstrate the importance of emotions to the daily lives of the subjects. Their behaviours often vary completely according to their mood. Interestingly, many appear sensitive to other's moods and can detect changes in the carer's tone of voice. This seemed to play an important part in a 'sense of humour'. Humour has never been commented upon in people with profound handicap, but I found it to be extremely highly valued by their carers.

#### 4. Results of the Video Analysis

The results are divided into fifteen parts, with each part showing the results for a group of categories measured. Results are presented in a series of tables, with comments on the important findings. Tables vary according to whether duration or number was coded: Where duration was coded, figures are given as percentages of total session time, unless stated otherwise; where number was coded, the total number of the events that occurred during the session is given.

##### 4.1 Session Time

All but two sessions were 600 seconds long. These were 592 and 355 seconds long. In both cases, the staff considered that no behavioural characteristics were lost because the sessions were cut short. In one case a session was interrupted by circumstances outside of the participants control. In the other the carer was unwilling to continue the sessions because of the behaviour of the subject.

##### 4.2 Characteristics of the Partner

This table shows the results of the video analysis for the categories involving the partner. It covers the duration of the partner's attempts at engagement, and the duration of the different techniques that were used. Results are shown in terms of a percentage of the total session time. The proportion of the 66 partners performing a behaviour is also given. Thus, 45 of the 66 used objects with the subjects, the mean amount of use being 19% of the overall total session time.

CATEGORY:	PARTNERS:	MEAN:	STD. DEV.:	MIN:	MAX:
Total engagement of partners	66/66	91.4%	13.2%	20.9%	100.0%
Partner's use of objects	45/66	19.1%	22.6%	00.0%	81.0%
Partner's use of physical contact	65/66	53.5%	33.1%	00.0%	00.0%
Partner's use of active phys. cont.	65/66	37.4%	27.5%	00.0%	98.7%
Partner's use of food	17/66	05.8%	14.5%	00.0%	73.8%

All partners attempted to engage the subjects, and most attempted engagement for most of the time, with the mean being very high at 91.4% of total session time. The exceptions were usually partners working with very difficult subjects. Most partners (45) tended to use objects to get the subject's attention. The objects used were almost exclusively soft toys, although musical toys were also quite popular. Physical contact was used by nearly all of the partners (65), but most often this involved supporting physically handicapped subjects. A more accurate assessment of the use of physical contact as a means of encouraging engagement is the 'active physical contact' category, which involved such actions as stroking, rubbing, tapping, jerking and, pulling. This was used by all but one partner, and amounted to a mean of 37% of the session time. Food was not used by many partners. The subjects that this was used with were generally the more difficult ones, for whom the use of food was supposed by the partner the surest method of gaining attention.

Most of these results are not very surprising. The partners tried hard to get engagement, and used a variety of techniques. Part 4.5 looks at the success of these techniques.

#### *4.3 Total Engagement of the Subjects*

The table below shows the total engagement of the subject during the sessions. This includes engagement with the partner, playing with objects (not stereotypic play), and attention to events other than the partner. Results are shown in terms a percentage of the total session time.

<u>CATEGORY:</u>	<u>SUBJECTS:</u>	<u>MEAN:</u>	<u>STD. DEV.:</u>	<u>MIN:</u>	<u>MAX:</u>
Total engagement of subjects	66/66	69.5%	21.6%	10.5%	99.6%

These results are important. On average, the subjects were engaged for just under 70% of the session time, which is a remarkably high figure.

Similarly remarkable is the fact that even the least able of the subjects attended for 10% of the session time. This shows that even the most impaired of the subjects is aware of the surroundings and clearly demonstrates this awareness to at least a small degree. Some of the subjects were engaged with their environment for almost the entire session. The theory of the "vegetative" person with a profound handicap



"showing no awareness of his surroundings" mentioned in the first chapter is not confirmed by these results.

#### 4.4 Engagement of the Subjects to the Partner

This table shows the engagement of the subjects to the partner. The results are shown in terms of a percentage of the total time that the partner attempted to engage with the subject. The engagement of the subjects is also divided into positive (sociable) and negative (actively resisting) engagements.

CATEGORY:	SUBJECTS:	MEAN:	STD. DEV.:	MIN:	MAX:
+ve engagement to partner	66/66	60.2%	23.2%	05.3%	97.4%
-ve engagement to partner	23/66	03.4%	09.5%	00.0%	61.8%
Total engagement to partner	66/66	63.6%	21.3%	12.1%	97.4%

Overall, these figures are very high. It will be noted that all subjects engaged with the partner for some length of time. The highest score shows that one subject engaged with a partner for 97.4% of the time that the partner attempted engagement, which is *extremely* high.

23 of the subjects also resisted engagement. Though overall resisted engagement accounted for only 3.4% of the total time subjects spent engaged with a partner, this is still a surprising finding, and suggests that the subjects play an active role in controlling their immediate environment.

Generally a picture of the sociability of people with profound handicap is emerging, though individual variations and the presence of active resistance to social engagement should be noted. Nevertheless, these figures for engagement once again indicate a high level of awareness of and responsiveness to the environment in people with profound handicap.

#### 4.5 Engagement of Subject to Partners Techniques

This table shows the subjects engagement to the partner whilst the partner used different techniques (e.g. objects or physical contact) to gain attention. Results are shown in terms of a percentage of the total time the partner used that technique, and also show the number of subjects who responded.

CATEGORY:	SUBJECTS:	MEAN:	STD. DEV.:	MIN:	MAX:
+ve eng. to use of object	42/45	67.4%	31.7%	00.0%	100.0%
-ve eng. to use of object	4/45	03.3%	15.6%	00.0%	100.0%
Total eng. to use of object	43/45	70.7%	29.7%	00.0%	100.0%
+ve eng. to use of physical contact	65/65	65.5%	26.0%	02.7%	100.0%
-ve eng. to use of physical contact	22/65	04.1%	11.7%	00.0%	67.6%
Total eng. to use of physical contact	65/65	69.7%	24.2%	05.5%	100.0%
+ve eng. to use of active phys. cont.	65/65	67.2%	26.4%	02.7%	100.0%
-ve eng. to use of active phys. cont.	20/65	04.2%	11.9%	00.0%	67.6%
Total eng. to use of active phys. cont.	65/65	71.4%	25.0%	05.5%	100.0%
+ve eng. to use of food	17/17	76.1%	29.4%	26.0%	100.0%
-ve eng. to use of food	5/17	05.9%	18.0%	00.0%	74.0%
Total eng. to use of food	17/17	82.0%	24.7%	30.4%	100.0%

When the partner used an object to get or hold the subject's attention, all but 2 of the subjects responded at some time during the session. Only 4 of the subjects responded negatively, although 3 of these also responded positively on different occasions. Use of object was clearly a successful method of attracting engagement.

As mentioned before, partners tended to be in physical contact with subjects who were physically handicapped, and used physical contact as a means of support rather than as a method of achieving interaction. The negative reactions to this should therefore be seen more as indications that physical contact is not sufficient to maintain engagement rather than that passive physical contact can produce negative reactions alone. Active physical contact was more obviously effective in obtaining engagement, although some 20 subjects resisted engagement during periods of the partner's active contact. Much seemed to depend on the mood of the subjects, and resistance to active contact could be replaced a short time later with positive engagement.

Food was highly successful in gaining engagement, which is not surprising. Five subjects resisted engagement whilst the partner used food, showing that the will

of the subject (i.e. the wish to resist engagement) can override the very strong attraction for food.

These results give an indication of the response of the subjects to these techniques. Clearly, such a table cannot show the subtleties of interaction, but an impression is created of a general responsiveness to most techniques used to gain attention, which is modified by the subjects mood.

#### *4.6 Engagement of the Subjects to Events and Objects*

This table gives more details of the time subjects were not engaged to the partner, but were engaged to other events that were occurring during the session (e.g. attending to events through a window or to the camera), or playing with objects. The table also gives a figure representing each subjects total interest in objects by adding this last figure to the previous figure for engagement to the partner whilst he used an object. Lastly, it gives a figure for the length of time any subjects mouthed objects.

CATEGORY:	SUBJECTS:	MEAN:	STD. DEV.:	MIN:	MAX:
Engagement to other events	43/66	08.5%	14.1%	00.0%	75.5%
Engagement to objects	33/66	08.1%	14.2%	00.0%	80.6%
Total interest in objects	47/66	29.7%	23.5%	00.0%	91.6%
Mouthing of objects	4/66	00.6%	03.2%	00.0%	24.8%

Over half of the subjects attended an event other than the partner during the session. This demonstrates a high level of awareness to the surroundings in the subjects, and perhaps a short attention span.

Half of the subjects engaged to objects during the session, although most did so for short periods of time and found the partner much more interesting. In two cases, however, the subjects proved to be absorbed in manipulating objects and preferred this to object manipulation by partners.

When engagement with a partner using objects is added to the previous figure, well over half of the subjects can be seen to have some interest in objects.

Few subjects (4) were seen to put objects in their mouths during the sessions, although one subject did spend a quarter of the session doing this.

#### 4.7 Total Number of Engagements

This table gives the number of separate engagements that occurred during the session for each subject. Figures represent the number for each subject.

<u>CATEGORY:</u>	<u>SUBJECTS:</u>	<u>MEAN:</u>	<u>STD DEV:</u>	<u>MIN:</u>	<u>MAX:</u>	<u>TOTAL</u>
<u>NO:</u>						
Total No. +ve engagements	66/66	11.5	04.7	01.0	25.0	763/826
Total No. -ve engagements	23/66	00.9	01.8	00.0	09.0	63/826

During the sessions there were a total of 826 engagements for all subjects, of which 763 were positive, and 63 negative. Thus, the great majority of engagements (92%) were positive. All subjects had at least one positive engagement, with a mean of 11.5 each. 23 subjects - quite a high number - had negative engagements, and these subjects had a mean of 2.7 negative engagements each. The mean length of engagements was 32.2 seconds, which, since the vast majority of engagements were terminated by the subjects (as section 4.8 shows), suggests that attention time may be fairly short in the majority of subjects.

#### 4.8 Initiations and Terminations of Engagements by the Subjects

This table gives the number of initiations and terminations of engagements by the subjects.

<u>CATEGORY:</u>	<u>SUBJECTS:</u>	<u>MEAN:</u>	<u>STD DEV:</u>	<u>MIN:</u>	<u>MAX:</u>	<u>TOTAL</u>
<u>NO:</u>						
Initiations by subject	13/66	00.6	01.9	00.0	11.0	42/826
Terminations by subject	66/66	08.7	04.9	01.0	24.0	579/826

Only 13 subjects initiated any engagements, and engagements initiated by subjects accounted for only 5% of the total. Even in many of these cases, it is hard to separate the act by the subject that initiated an engagement with preceding actions by a carer, which may have prompted that action.

Generally, interactions with people with profound handicap involve considerably greater effort on the part of the non-handicapped partner. Over 70% of engagements were terminated by the subjects, which illustrates the difficulties carers have in maintaining engagement, and again indicates that people with profound handicap have a short attention span.

#### 4.9 Events Preceding Engagements

This table shows the events which immediately preceded the beginning of an engagement, and gives an indication of the most popular methods used by the partners to initiate an engagement. The events which were coded were: use of vocalization, use of object, use of active physical contact, use of food, use of teasing, and event unknown.

<u>CATEGORY:</u>	<u>SUBJECTS:</u>	<u>MEAN:</u>	<u>STD DEV:</u>	<u>MIN:</u>	<u>MAX:</u>	<u>TOTAL</u>
<u>NO:</u>						
+ve eng.: Vocalization	42/66	02.9	03.5	00.0	13.0	197/826
-ve eng.: Vocalization	1/66	00.1	00.3	00.0	03.0	3/826
+ve eng.: use of object	37/66	02.6	04.1	00.0	21.0	172/826
-ve eng.: use of object	1/66	00.1	00.2	00.0	01.0	2/826
+ve eng.: use of physical contact	53/66	03.4	03.5	00.0	15.0	230/826
-ve eng.: use of physical contact	19/66	00.7	01.5	00.0	08.0	46/826
+ve eng.: use of food	14/66	01.0	03.0	00.0	22.0	64/826
-ve eng.: use of food	1/66	00.1	00.2	00.0	02.0	2/826
+ve eng.: use of teasing	2/66	00.1	00.1	00.0	01.0	2/826
-ve eng.: use of teasing	0/66	00.0	00.0	00.0	00.0	0/826
+ve eng.: event unknown	32/66	00.7	00.9	00.0	03.0	56/826
-ve eng.: event unknown	2/66	00.1	01.0	00.0	08.0	10/826

This table shows that the event which most often preceded an engagement was use of active physical contact by the partner, which accounted for 33% of the total, though in a large number of cases (46), this engagement was negative. Engagements initiated entirely by vocalizations were next in popularity, accounting for 24% (though, of course, many of the other categories also included a vocal component). Use of objects initiated only slightly fewer engagements, and as all but two of these were positive, it appears to be a very successful strategy for gaining the subject's attention. Food and teasing initiated engagement much less often. The number of occasions where no specific preceding event could be determined ('unknown') was quite high (these did not include subject initiated engagements, which were separately identified).

#### 4.10 Expressiveness of Subjects

This table gives the duration of a variety of expressive behaviours of the subjects, as a percentage of the total session time.

CATEGORY:	SUBJECTS:	MEAN:	STD. DEV.:	MIN:	MAX:
Total facial expression	57/66	13.7%	14.1%	00.0%	49.3%
Happy facial expression	55/66	12.4%	14.0%	00.0%	49.3%
Sad facial expression	17/66	01.2%	03.2%	00.0%	18.6%
Angry facial expression	3/66	00.6%	00.4%	00.0%	03.5%
Frightened facial expression	0/66				
Crying	4/66	00.2%	00.8%	00.0%	05.3%
Appropriate laughter	24/66	01.6%	03.8%	00.0%	16.5%
Appropriate smiling	53/66	12.1%	14.3%	00.0%	49.3%
Inappropriate laughter	24/66	00.02%	00.08%	00.0%	00.3%
Inappropriate smiling	24/66	00.2%	00.8%	00.0%	06.0%
Eye contact	34/66	04.2%	11.0%	00.0%	84.7%

The majority of subjects clearly displayed unambiguous facial expressions for at least a part of the session, though nine subjects did not. The facial expression most frequently presented was a happy one, which, as the sessions were mostly treated as play, is not surprising. This was mostly made up of appropriate smiling (i.e. coordinated with the carer's actions), which in one subject accounted for half of the session time. Other facial expressions were also seen, including sad and angry expressions, and - in four subjects - crying. Inappropriate smiling and laughter was rather frequent considering the short length of the sessions, and this may be taken to indicate that in at least some instances the expressions were deficient in control..

Considering the small sample of time taken, these results represent a rich variety of expressive patterns. Taking into account inappropriate expression, however, their regulation in interpersonal contact is less certain. Analysis showed that 5 of the subjects laughed at teasing, and that one laughed at an emotional outburst during the session, but neither of these events occurred frequently enough to draw any firm conclusions about the causes of laughter in these cases. Generally, the event preceding bouts of laughter seemed to be a playful approach from the carer, and this occurred often enough to suggest that in the majority of subjects expressions are used appropriately in interaction and do serve a regulatory function.

Interestingly, over half of the subjects managed to achieve eye contact during the session. There were large individual differences: although the mean was only 4%, one subject held eye contact for 84% of the session. In general, eye contact appeared to be



infrequent, unreliable and of short duration in most cases, and it rarely appears to be used as a regulator of interaction. It should also be noted that eye contact is very difficult to code from video, where the subject's orientation varies widely. The presence of at least some eye contact can be confirmed with certainty, however, and its occurrence in so many of people with profound handicap is encouraging.

#### 4.11 Physical Contact Initiated by the Subjects

In this table, the number of times subjects touched, pushed or scratched the partner is given. Results are based on number for each subject.

CATEGORY:	SUBJECTS:	MEAN:	STD. DEV.:	MIN:	MAX:
Touces	41/66	03.7	07.0	00.0	38.0
Pushes	19/66	00.3	00.9	00.0	05.0
Scratches	16/66	00.2	01.2	00.0	08.0

The number of subjects that touched a carer during the session, and therefore initiated some physical contact, was 41 of the 66, which is an unexpectedly high number. Furthermore, these subjects obviously respond to physical contact and were able to take an active part in the interaction with the partner.

A significant number of subjects pushed or scratched their carers. This was usually part of a negative engagement, directed to stop the partner from coming too close, but at least one carer believed that scratching was in fact used as a positive way of communicating by a subject.

#### 4.12 Number of Sounds made

This table gives the results of the analysis of the number of sounds and words made by the subjects.

CATEGORY:	SUBJECTS:	MEAN:	STD. DEV.:	MIN:	MAX:
Number of sounds made	62/66	32.1	39.1	00.0	229.0
Number of different sound-types made	62/66	01.5	01.5	00.0	09.0
Number of words made	3/66	00.1	00.7	00.0	05.0

Only three of the subjects made any words, and these were repetitions of words spoken by the partner. Most made sounds, though there was generally little variety in the sound types. Usually, a subject used only one or two sounds (such as an 'ah' sound, for example), and repeated this throughout the session.

#### 4.13 Duration of Sounds made

This table shows the duration of sounds made as a percentage of the session time, and as a percentage of the time that the subjects were engaged. It also shows whether proportionally more sounds were made during engagements than would be expected by chance, and the percentage of sounds that may be being used in a turn-taking pattern.

CATEGORY:	SUBJECTS:	MEAN:	STD. DEV.:	MIN:	MAX:
Total duration of sounds	62/66	82.0%	24.7%	30.4%	100.0%
Sounds during engagements	59/62	64.9%	32.5%	00.0%	100.0%
%above expected from chance	45/59	06.0%	20.5%	-48.0%	44.8%
%sounds used in turntaking	21/59	04.6%	11.8%	00.0%	53.8%

On average, subjects made sounds throughout 80% of the session time and in 64.9% of the engagements. In line three of the table, the number of sounds made during engagements is compared with what would be expected by chance. For each subject, a percentage is obtained for the proportion of all sounds that were made during engagements and is compared with the percentage of the total session time that the subject engaged for. If the two percentages are the same, then the percentage of sounds made during engagements was at a chance level. This calculation can be represented by a formula:

$$\left( \frac{\text{sounds made during engagements}}{\text{sounds made during the session}} \times 100 \right) - \left( \frac{\text{duration of engagement}}{\text{duration of session}} \times 100 \right)$$

% sounds in engagements                      % engagement in session

The results of this showed that overall subjects used sounds during engagements 6% more than expected by chance. This seems to indicate that subjects behave differently during engagements, making significantly more sounds. The sounds produced by the subjects may therefore have an element of a communicative purpose. Some subjects, it was noted, used sounds only during periods of engagement.

Some form of turntaking behaviour was seen in 21 of the subjects, but in most cases this may represent a skilful management of an interaction by the partner. In at least one case, however, the initiative for the turntaking seemed to lay with the subject.

#### 4.14 Stereotyped and Self-Injurious Behaviour

The table shows the duration of stereotyped and self-injurious behaviour as a percentage of total session time

CATEGORY:	SUBJECTS:	MEAN:	STD. DEV.:	MIN:	MAX:
Duration of stereotyped movements	28/66	12.0%	23.5%	00.0%	100.0%
Duration of self injurious behaviour	4/66	00.9%	06.9%	00.0%	56.7%

Few subjects showed any self-injurious behaviour, but one subject did so for over half the session. Stereotopic behaviour was seen in 28 subjects, and was observed in some subjects during the whole session.

#### 4.15 Other Aspects of the Subject's Behaviour

The last table shows the number of occurrences of several behaviours.

CATEGORY:	SUBJECTS:	MEAN:	STD. DEV.:	MIN:	MAX:
Number of requests by subjects	9/66	00.7	02.6	00.0	17.0
Number of acts demonstrating learning	14/66	00.3	00.7	00.0	03.0
Number of imitations by subject	3/66	00.1	00.7	00.0	05.0
Number of mood changes of subjects	7/66	00.1	00.5	00.0	03.0

Nine of the subjects used requests directed at their partner during the sessions, and fourteen carried out acts which demonstrated some learning. One behaviour which combined both was a request for foot stroking made by one subject, who raised his foot up to the carer. Imitations were seen in only three subjects, and were vocal in all cases. Mood changes were seen in seven subjects, which, considering the length of the sessions, is extraordinarily high. One possible reason for this may be bad humour at having a morning or afternoon disrupted by an unscheduled play session, when the subjects in question may well have preferred to sleep, but carers suggested that this was an accurate reflection of the subjects mood changes.

#### *4.16 Some Observations on the Video Analysis Results*

The initial results of the video analysis shows that the interactions between the subjects and their partners are much poorer than those seen in infants: they depend much more on the carer to adapt their behaviour to match the subjects, the interactions are short and spasmodic, and the social behaviours of the subjects are limited (e.g. eye contact).

Despite these reservations, the results have revealed further interesting facts about people with profound handicap, systematically confirming the beliefs in the competencies of people with profound handicap often held by their carers. These findings can be summarized as follows: they attend to and respond to their environment and their carers; some may occasionally initiate an interaction or physical contact; some may request an action from their carer; they are generally responsive to physical contact and the use of objects by carers; some may respond to approaches by carers negatively in that they actively choose to resist contact; they behave differently during interactions, for example by making more sounds; and they are capable of using a variety of expressive behaviours, demonstrating an active emotional system.

### **5. Further Statistics**

The initial results from the questionnaire and the video analysis were used in a series of statistical analyses which investigated aspects of particular interest identified in Chapter 3. These analyses looked for differences between groups divided by the factor under investigation, such as medication, which divides the subjects into one group receiving and one group not receiving drugs. The procedure used was a Mann-Whitney test of difference, and the results presented show all variables which differentiated the groups to levels of significance of  $<.001$ ,  $<.01$  and  $<.05$ .

#### *5.1 Mobility*

The cause of physical handicap in the subjects was either Cerebral Palsy - a dysfunction of motor control due to pathology of the motor centres of the brain - which was implicated in the majority of cases, or Spina Bifida, a defect in the prenatal development of the structure of the bones of the spine.

There is a large body of work describing the effects of these conditions on normal development. The most obvious consequence is in the reduced capacity of the young child to interact with the environment of people and objects around him. This may have far-reaching cognitive and perceptual consequences: the development of size constancy - necessary for a stable visual environment - has been found to relate directly to amount of experience of being independently mobile (Wedell, Newman, Reid and Bradbury, 1972).

Immobility may also have consequences for emotional development, especially if the child is hospitalized, which may result in a serious lack of somatosensory stimulation. Prescott (1976) suggests that this is a fundamental cause of behavioural problems - more important as a cause, in fact, than the child's original impairment.

Mother-infant interaction may also be distorted by the physical appearance of the child, though the basic techniques of child rearing used by the mother seem largely unaffected, except for potentially serious over-attention to physical aspects of development (Shere and Kastenbaum, 1966).

As well as the obvious problems of immobility, problems may also be caused by poor fine motor control, which has the potential to seriously delay development. Anderson and Spain (1977) have pointed out that this also applies to spina bifida children who until recently have been assumed to suffer from dysfunction of the lower limbs only. Some spina bifida and cerebral palsy children have severe impairment in visuo-motor co-ordination skills. Many have problems in adjusting prehension.

How much a physical handicap will affect the development of someone with profound mental handicap is not clear. Many of the problems described above will simply be overlaid by the larger problems associated with a mental handicap. It is worthwhile, however, to compare subjects who are physically handicapped with those who are not, although caution must be taken in interpreting results as there may be several confounding factors (for example, the physically handicapped could be more brain damaged generally, and therefore less able).

The physically handicapped subjects scored differently on the following:

<.001	<.01	<.05
<i>QUESTIONNAIRE:</i>		
Visual Handicap (poorer)	Head Control (poorer)	Sex (female)
Hand Control (poorer)	Visual Tracking (poorer)	Psychiatric Drugs (less)
Self Help Skills (poorer)	Acts on Carer (less)	Sleep Disturbance (less)
	Turn-Taking (more)	Spontaneous Learning (less)
		Responsiveness (more)
		Response to Individuals (more)
		Happy Expressions (more)
		Fear of Situation (more)
<i>VIDEO ANALYSIS:</i>		
	Act Showing Learning (less)	Shuns Engagements (less)
		Stereotopy (less)

There is no tendency towards unresponsiveness or lack of awareness in the non-mobile. Physical handicap is likely to be associated with visual handicap, other aspects of motor handicap, and poor self help skills, as might be expected. Similarly, the physically handicapped demonstrated acts of learning, stereotopy, and termination of engagements much less than subjects who were physically more able. The reduced examples of learning and termination (and control) of engagements may be explained by either the lack of opportunity produced by the limitations of the physical handicap, or else the lack of the ability itself. In view of the absence of any difference in observed responsiveness - the carers actually reported them to be more responsive in the questionnaires - the first explanation is the more likely.

## 5.2 Visual Handicap

The effect of visual impairment on normal development is characterized by a delay: generally, the more severe the impairment, the more serious the delay. Delays have been identified in a variety of areas of development: social adaptation; sensorimotor understanding (the properties of objects and relations between them); exploration of the environment; verbal comprehension; and the structure and content of expressive language (Warren, 1977).

Although motor development is usually normal (though there are problems in fine control due to the lack of visual feedback), blind children do not attempt exploration and manipulation of the surrounding world, which may have a crucial



effect on the child's construction of reality and early cognitive development (Fraiberg, 1968).

Mother-infant interactions may also be seriously affected (Fraiberg, 1979), vision (especially eye contact) playing a crucial part in regulation, and carers may become less communicative or over-protective.

There is a higher degree of behaviour disorder and psychiatric illness in blind children caused by an interaction of psychological, developmental, attitudinal and social factors (Jan, Freeman and Scott, 1977). The lack of stimulation can also lead to stereotyped self-stimulation behaviours such as body-rocking, eye rubbing and poking, and waving hands in front of the face. Generally, visually impaired children have a tendency for self-directed rather than outer-directed behaviours, which in Piaget's theory is crucial for sensorimotor development.

Once more, nothing is known about the effect of these problems on the development of people with profound handicap, although many will be overlaid by the wider problems of mental handicap. A comparison was made using presence of blindness or near blindness as the control variable.

The visually handicapped scored differently on the following:

<.001	<.01	<.05
<i>QUESTIONNAIRE:</i>		
Spontaneous Learning (less)	Residence (hospital)	Self Help Skills (less)
Orients to Person (less)	Phenobarbitone (more)	Epilepsy (more)
Orients to Event (less)	Mobility (poorer)	Initiates Interaction (less)
	Liking for Travel (less)	Fearful Expressions (less)
		Laughter at Outburst (less)
<i>VIDEO ANALYSIS:</i>		
Engages Other Event (less)	Total Engagement (less)	Engages Partner (less)
Eye Contact (less)	Resists Engagement (more)	Plays with Objects (less)
Partner Act PhysCon (more)	No. of Resists (more)	Engages to Act PhysCon (less)
Partner Phys Con (more)	Resists Act PhysCon (more)	Engages to Phys Con (less)
	Resists Food (more)	Resists Phys Con (more)
	Prec Event/Res: Food (more)	Self Injury (more)
	Prec Event: Physical (more)	Prec Event: Vocal (less)
	Prec Event: Food (more)	Prec Event/Res: PhyCon (more)
	Partner Engages (more)	

Visually handicapped subjects were more likely to be in hospital, to be non-mobile, to be on phenobarbitone and to be poor at self-help skills and learning. There

was also significant differences in total engagement time. The partners in the videotaped sessions tended to use physical contact more with the visually handicapped, but overall they responded to it less.

The visually handicapped also showed a tendency towards behaviour problems. There was significantly more examples of attempted engagement being actively resisted and increased self-injurious behaviour.

Interestingly, these findings seem to confirm that the same problems occur in the development of the visually impaired child with profound mental handicap as the visually impaired 'normal' child: there is a problem in responsiveness, in learning, and evidence of behaviour problems, although higher rates of stereotypy were not found (which is probably due to the generally high level in people with profound handicap).

### 5.3 Drug Use

The effects of medication is an important issue which has recently been the focus of concern. Many people with profound handicap are on a variety of drugs, many of which have serious side effects, most commonly an increased drowsiness. This study divided drug use into four categories: anti-epileptic drugs; Phenobarbitone (a sedative used as an anti-epileptic); Benzodiazapines (minor tranquillizers); and psychiatric drugs (major tranquillizers such as the Phenothiazines).

This first comparison looked at those subjects receiving medication in any or all of these categories, and compared them with those receiving no medication. The group of subjects receiving medication scored differently on the following:

<.001	<.01	<.05
QUESTIONNAIRE:		
Epilepsy (more)	Self Help Skills (less) Yes/No (less)	Interest in Objects (less) Objects in Mouth (less) Inappropriate Laughter (more) Inappropriate Smiling (more)
VIDEO ANALYSIS:		
	Total Engagement (less)	No. of Engagements (less) Plays with Objects (less) Engages to Food (less)

Epilepsy is frequent, this being the common reason for medication. Subjects on medication are poorer at self help skills. They are also less interested in objects,

something which the carers reported in questionnaires and which was confirmed in the video analysis. Carers also reported increased inappropriate smiling and laughter, which was not confirmed, possibly because of the short duration of the video session.

One important result is the reduced engagement of the medication group, which confirms fears of sedative side-effects. It shows that these side-effects are just as important when the user has a profound handicap as they are with non-handicapped patients.

#### 5.4 Anti-Epileptic Drug Use

Anti-epileptic drugs are the most popular amongst people with profound handicap. There are several commonly prescribed anti-epileptic drugs, including Phenytoin, Carbamazepine and Sodium Valporate. The last two are considered less toxic, but it is not always possible to prescribe them since it is possible to habituate to them and their effects wear off. All of these drugs were being prescribed to subjects during the study.

Anti-epileptic drugs have side effects ranging from drowsiness, ataxia (unsteady gait), and dysarthria (impairment of sound production). Some of the effects can be quite subtle, and they are commonly associated with impaired cognitive function and progressive deterioration which may be global (particularly with Phenytoin) or specific (with the other anti-epileptic drugs). One major problem is that unlike other patients receiving medication, people with profound handicap cannot report these more subtle effects when they occur.

The group receiving anti-epileptic drugs scored differently on the following:

	<.001	<.01	<.05
QUESTIONNAIRE:			
Epilepsy (more)			Awareness (less) Self Help Skills (less) Yes/No (less)
VIDEO ANALYSIS:			
	Total Engagement (less)		Engages Partner (less) No. of Engagements (less) Sounds in Engagements (less) Resists Food (more)

Carers considered those receiving anti-epileptic medication to have a reduced awareness. This is confirmed in the finding from the video analysis that these subjects had lower scores for engagement during the sessions. They were also less likely to make sounds during engagements.

This may, of course, be attributed to either of two causes: the side effects of the drugs, or a reduced level of ability in those subjects who suffer from epilepsy.

### 5.5 Phenobarbitone Use

Phenobarbitone is a barbiturate and a sedative drug. It is occasionally prescribed as an anti-epileptic. The side effects of severe drowsiness, and confusion in the elderly, are now well known and it has been much less commonly prescribed in recent years. It is also extremely addictive. A number of subjects were taking it, however, and in view of it's reputation it was thought worthwhile to use it as a separate variable.

A comparison was therefore made using Phenobarbitone use as the control variable. The group receiving Phenobarbitone scored differently on the following:

	<.001	<.01	<.05
QUESTIONNAIRE:			
	Age (older)		Spontaneous Learning (less)
	Residence (hospital)		Activity (less)
	Visual Handicap (more)		Liking for Travel (less)
	Acts on Carer (less)		Interest in Objects (less)
	Eye Contact (less)		Words (less)
	Visual Tracking (poorer)		Happy Expressions (less)
			Appropriate Smiling (less)
			Laughter at Teasing (less)
VIDEO ANALYSIS:			
	Scratches (more)		Total Engagement (less)
			No. of Resists (more)
			Engages Act Phys Cont (less)
			Resists Act Phys Cont (more)
			Eye Contact (less)
			Inappropriate Laughter (more)
			Imitation (more)
			Prec Event: Physical (more)
			Prec Event/Res: Phys Cont (more)
			Partner Act Phys Cont (more)

Phenobarbitone use was associated with residence in hospital, more visual handicap and older subjects (mean age 52 for those receiving phenobarbitone compared to 30 for those not).

Interestingly, carers did not rate them badly on responsiveness, but the video analysis showed a significant decrease in engagement time and an increase in the number of actively resisted engagements. Questionnaire and video analysis showed reduced eye contact, and the video analysis also showed increased inappropriate laughter, which some carers thought was associated with drug use. (The analysis also showed increased imitation, which is an artifact produced by one subject receiving phenobarbitone who mimicked words).

Generally, these results tend to confirm the powerful sedative effects of Phenobarbitone (though again they may also reflect the ability level of those who are prescribed it).

### 5.6 Benzodiazapine Use

Another group of drugs which are commonly prescribed to people with profound handicap are the tranquillizers. Historically, these were intended to make hospital residents more manageable. Today, they are most commonly prescribed to induce sleep at night. The group which is most popular are the Benzodiazapines, of which Diazepam (Valium), Nitrazepam (Mogadon) and Clobazam were being taken by subjects. The side effects of these drugs include drowsiness, fatigue, ataxia and confusion.

The subjects receiving Benzodiazapine scored differently on the following:

	<.001	<.01	<.05
QUESTIONNAIRE:		Sleep Disturbance (more)	Psychiatric Drugs (more) Epilepsy (more) Appropriate Laughter (less)
VIDEO ANALYSIS:			Engages to Other Event (more) Engages to use of Objects (less) Engages to Phys Cont(more) Partner Engages (less) Partner uses Object (less)

Amongst those receiving medication there was more sleep disturbance and a tendency for its use to be associated with psychiatric drugs. These subjects did not engage for significantly less time, and actually seem to attend to events more. This

may be due to the low dosages involved, and the fact that they were usually prescribed to induce sleep and taken only in the evening.

5.7 Psychiatric Drug Use

Psychiatric drugs are not prescribed as often to people with profound handicap, but are used on some occasions. These powerful drugs are major tranquillizers and are used for treating psychiatric illness such as depression. Subjects in the study were receiving Thioridazine and Chlorpromazine (Largactil), both of which can have sedative effects in large doses. They can also produce 'Parkinson disease'-like twitches of limbs.

A comparison was also made using psychiatric drug use as the control variable. The group receiving psychiatric drugs scored differently on the following:

<.001	<.01	<.05
QUESTIONNAIRE:		Benzodiazapine (more)
		Mobility (better)
		Appropriate Laughter (less)
		Appropriate Smiling (less)
		Mood Expression (more)

VIDEO ANALYSIS:  
The subjects on psychiatric drugs did not differ significantly on any variables.

There were no very significant trends, though very few subjects are receiving psychiatric drugs, and the dosage is low. Generally there is an association with Benzodiazapine and carers rated them low on appropriate laughter and reduced smiling. Not surprisingly given the nature of the drugs and the purposes for which they are prescribed, they were rated as having larger mood swings.



### 5.8 Residence

Comparison of residence between those living at home and those in institutions was an obvious one to make. In Chapter Three I discussed the studies which have been carried out with people with profound handicap on the effects of leaving and staying in an institution. This study included many who were living at home, and a comparison could easily be made.

The group living in hospital scored differently on the following:

<.001	<.01	<.05
<b>QUESTIONNAIRE:</b>		
Age (higher)	Phenobarbitone (more)	Visual Handicap (poorer)
Spontaneous Learning (less)	Laugh at Outburst (less)	Visual Tracking (poorer)
Activity (less)	Liking for Travel (less)	Knows Cause-Effect (less)
Responsiveness (less)		Orients to Person (less)
Interest in Objects (less)		Orients to Event (less)
Response to Individuals (less)		Attention Span (less)
Acts on Carer (less)		Initiates Interaction (less)
Eye Contact (less)		Physical Contact (less)
Happy Expressions (less)		Proximity (less)
Appropriate Smiling (less)		Appropriate Laughter (less)
Liking for People (less)		Fear of Strangers (less)
Liking for Music (less)		Fear of Situation (less)
		Emotional Sensitivity (less)
		Laughter at Teasing (less)
		Response to Anger (less)
<b>VIDEO ANALYSIS:</b>		
Engages Other event (less)	No. Resists (more)	Total Engagement (less)
Eye Contact (less)	Prec Event: Phys Con (more)	Engages to Partner (less)
Prec Event: Vocal (less)	Prec Event: Unknown (more)	Resists Engagement (more)
Partner Act PhysCon (more)	Partner Engages (more)	Engages to use of Object (less)
	Partner Phys Cont (more)	Engages to Phys Cont (less)
		Engages to Act Phys Cont (less)
		Resists Act Phys Cont (more)
		Act Showing Learning (less)
		Partner uses Food (less)

There were many differences. Generally, the questionnaire showed that the hospital group were less responsive across a variety of variables, and less likely to show a liking for people or things. They were also older than those living at home (mean age 41 versus 22). Similar conclusions can be drawn from the video analysis, where the hospital group were engaged for considerably less time, gave less eye contact, and resisted engagement more.

These findings are difficult to interpret. They may reflect a drift of the most

handicapped and unresponsive into hospitals (as seen in the higher ages), or the effect of the hospital environment. It is likely both play a part.

### 5.9 *Laughter at Outburst*

The ability to laugh at emotional outbursts in carers was considered an important characteristic. I therefore divided the subjects into those who demonstrated this ability and those who did not. This division was applied to the questionnaire and the video analysis results. This test showed that the group responsive to emotional outburst scored differently on the following:

<.001	<.01	<.05
<b>QUESTIONNAIRE:</b>		
Responsiveness (more)	Residence (home)	Activity (more)
Orients to Person (more)	Spontaneous Learning (more)	Physical Contact (more)
Orients to Event (more)	Knows Cause-Effect (more)	Visual Tracking (better)
Attention Span (more)	Awareness (more)	Yes/No (more)
Laughter at Teasing (more)	Interest in Objects (more)	Use of Facial Expression (more)
Eye Contact (more)	Initiates Interaction (more)	Angry Expressions (more)
Happy Expressions (more)	Turn-Taking (more)	Crying (more)
Liking for Music (more)	Liking for People (more)	Imitation of Carer (more)
Liking for Travel (more)		Fear of Strangers (more)
Emotional Sensitivity (more)		Response to Anger (more)
Laughter at Teasing (more)		
Appropriate Laughter (more)		
Appropriate Smiling (more)		
Responsiveness to Individuals (more)		
<b>VIDEO ANALYSIS:</b>		
Total Engagement (more)	Engages to Partner (more)	No. of Engagements (more)
Plays with Objects (more)	Engages to Phys Cont (more)	No. of Resists (less)
	Prec Event: Phys. (more)	Resists Engagement (less)
	Partner Uses Objects (more)	Engages to Other Events (more)
		Engages to Act PhysCont (more)
		Engages to Food (more)
		Stereotopy (less)
		Self Injury (less)
		Eye Contact (more)
		Use of Facial Expression (more)
		Happy Expressions (more)
		Appropriate Smiling (more)
		Turn-Taking (more)
		Imitation (more)
		Object in Mouth (more)
		Partner uses Object (more)

In both the questionnaire and the video analysis data, the group that laughed at emotional outbursts demonstrated significantly higher responsiveness and

expressiveness across a number of variables, combined with reduced maladaptive behaviours such as stereotypy, self-injury and resisting engagements. Therefore the ability to laugh at emotional outbursts seems to differentiate a comparatively able group. I will return to this subject in the next chapter.

## 6. Higher Order Statistical Analysis of the Data

This last part of the results section concerns more complex statistical procedures which were carried out on the initial data. The purpose was to determine any trends within the results, and to identify subgroups within the population. Using questionnaire and video analysis data, factor analysis and cluster analysis were performed.

### 6.1 Factor Analysis

The data from the questionnaire was put through a factor analysis. Eigenvalues from the principle components analyses are given below.

<u>FACTOR</u>	<u>EIGENVALUE</u>
1	13.89
2	5.06
3	4.03
4	3.67
5	3.11
6	2.72
7	2.20
8	2.10
9	1.94
10	1.76
11	1.57
12	1.51
13	1.34
14	1.28
15	1.18
16	1.11
17	1.00

An oblique (Oblimin) rotation was attempted but failed to converge. An orthogonal (Varimax) rotation did converge in 25 iterations, producing 17 factors. The most important of these factors are reproduced below, with the loading on the factor for each variable listed in brackets.

**FACTOR 1:**

Appr. laughter	(.8)	Sad Facial Expr.	(.3)	Shun	(-.3)
Laugh at tease	(.8)	Orients to Person	(.3)	Age	(-.3)
Appr. smiling	(.8)	Residence	(.3)		
Happy facial expr.	(.7)	Objects	(.3)		
Responsiveness	(.7)	Cries	(.3)		
Emotional sens.	(.6)	Orients to Event	(.3)		
Likes music	(.6)	Phenobarbitone	(.3)		
Laugh @ Outburst	(.5)	Eye contact	(.3)		
Response to Indivs.	(.5)	Sound-type	(.3)		
Likes People	(.5)	Stereotopy	(.3)		
Resp to Anger	(.5)	Psychiatric Drugs	(.3)		
Use of Facial Expr.	(.5)	Knows Cause-Effect	(.3)		
Attn Span	(.4)	Use of Yes/no	(.3)		
Likes Travel	(.4)				
Physical Con	(.4)				
Initiates	(.4)				
Awareness	(.4)				
Turn-Taking	(.4)				
Learning	(.4)				
Activity	(.4)				

Factor 1 is by far the most important factor, accounting for 22% of the variance. This factor can be described as a 'responsiveness' factor, loading highest on appropriate smiling and laughter, laughing at teasing, happy facial expression, responsiveness and similar variables. Shunning or terminating engagements loaded negatively, as did age.

**FACTOR 2:**

Vis. tracking	(.9)	Self injury	(.3)
Visual Handicap	(.8)	Attention span	(.3)
Eye Contact	(.8)	Imitates	(.3)
Orients to Event	(.6)	Interest in objects	(.3)
Orients to Person	(.6)	Laughs at outburst	(.3)
Learning	(.4)		
Likes travel	(.4)		

Factor 2 accounts for 8% of the variance, and can be called a 'visual handicap' factor, featuring variables such as visual tracking, orientation and eye contact.

## FACTOR 3:

Hand control	(.8)	Spontaneous learning	(.3)	Self injury	(-.3)
Mobility	(.8)	Sex	(.3)		
Self help skills	(.6)				
Head control	(.5)				
Response to anger	(.4)				
Acts on partner	(.4)				

Factor 3 accounts for 6.4% of the variance. This factor is concerned with physical handicap and also features variables such as hand control, self-help skills and acting on the partner.

## FACTOR 4:

Cries	(.7)	Shuns	(.3)	Age	(-.3)
Mood changes	(.7)	Anger facial expr.	(.3)	Self injury	(-.3)
Sad facial expr.	(.7)				
Mood expression	(.5)				

This factor accounts for 5.8% of the variance, and can be described as a 'moods' factor, featuring crying and mood variables.

## FACTOR 5:

Inappr laughter	(.9)	Head Control	(.3)	Use of yes/no	(-.3)
Inappr smiling	(.8)				

This factor accounts for 4.9% of the variance, and can be labeled an 'inappropriate expression' factor.

The data from the video analysis was also put through a factor analysis. Eigenvalues from the principle components analyses are given below.

<u>FACTOR</u>	<u>EIGENVALUE</u>
1	11.16
2	6.97
3	5.07
4	4.41
5	3.99
6	3.76
7	3.33
8	2.98
9	2.87

10	2.65
11	2.39
12	2.18
13	2.04
14	1.88
15	1.68
16	1.65
17	1.57
18	1.34
19	1.28
20	1.15
21	1.12

Again, an oblique rotation did not converge but an orthogonal (Varimax) rotation did converge in 22 iterations, producing 17 factors. Those accounting for more than 5% of the variance are reproduced below, with the loading on the factor for each variable listed in brackets.

**FACTOR 1:**

Engages partner tot.	(.8)	Visual Handicap	(.3)	Event: res: vocal	(-.3)
Total engagement	(.8)	Eng. to use of obj.	(.3)	Event: res: food	(-.3)
Engages phys. cont.	(.8)	Event: res: unknown	(.3)		
Number engagements	(.7)	Touches partner	(.3)		
		Acts of Learning	(.3)		

Factor 1 is the single biggest factor, and accounts for 14.3% of the variance. It can be described as a 'responsiveness' or 'engagement' factor, and features variables concerned with the total engagement of the subject. It also includes a high responsiveness to physical contact.

**FACTOR 2:**

Angry facial expr.	(.9)
Event: res: unknown	(.9)
Crying	(.8)
Sad facial expr.	(.8)
Mood changes	(.8)
Pushes	(.7)
Resists phys. con.	(.4)
Resists active phys.	(.4)

Factor 2 accounts for 8.9% of the variance, and is a 'negative mood' factor.



This includes angry and sad expressiveness, mood changes, and a tendency to resist physical contact.

**FACTOR 3:**

Imitation	(.9)	Age (older)	(.3)	Phenobarbitone (more)	(-.3)
Laughter @ outburst	(.8)				
Use of words	(.8)				
Sound types	(.7)				
Turn-taking	(.5)				
Laughter @ teasing	(.4)				
Inappropriate laugh.	(.4)				

Factor 3 accounts for 6.5% of the variance. It can be described as a use of 'words/sounds' factor, featuring imitation and turn-taking.

**FACTOR 4:**

Self-injury	(.9)	Prec Event: Res: Phys	(.3)
Resists engagement	(.8)		
Resists phys. cont.	(.8)		
Res. act phys cont.	(.8)		
Number of sounds	(.6)		

Factor 4 accounts for 5.7% of the variance, and can be described as a 'disturbed behaviour' factor, featuring self injury and a tendency to resist engagement.

**FACTOR 5:**

Facial expression	(.9)	Laughter @ teasing	(.3)	Learning	(-.3)
Happy fac. expr.	(.9)				
Appropriate smiling	(.9)				
Appropriate laughter	(.6)				

Factor 5 accounts for 5.1% of the variance and can be labeled 'happy expressiveness'.

In the factor analysis of the questionnaire data, the most important factor is clearly a 'responsiveness' factor, accounting for almost a quarter of the variance. The next important are visual and physical handicap factors, which together account for another 14.4%. Following these, a moods factor is fairly important, but all other factors account individually for less than 5% of the variance.

This is interesting, but as this is based upon the responses of carers, similar results from the video analysis data are more compelling. In the factor analysis of the video data, a responsiveness factor is again the most important, followed by a negative

mood factor and three other factors which account for greater than 5% of the variance: use of words or sounds, disturbed behaviour, and happy expressiveness.

Comparing the results of both factor analysis, the following factors were shown to be the most important:

FACTOR:	QUESTIONNAIRE: VARIANCE:	VIDEO ANALYSIS: VARIANCE:
Factor 1.	Responsiveness (22.0%)	Responsiveness (14.3%)
Factor 2.	Visual Handicap (8.0%)	Negative Mood (8.9%)
Factor 3.	Physical Handicap (6.4%)	Words/Sounds (6.5%)
Factor 4.	Moods (5.8%)	Disturbed Behaviour (5.7%)
Factor 5.	Inappropriate Expression (4.9%)	Happy Expressiveness (5.1%)

Responsiveness is the single biggest factor underlying both sets of results. Moods also feature prominently. It is also interesting to note the prominence of disturbed behaviour in the second factor analysis. The importance of visual and physical handicap is also intriguing, but may reflect the construction of the questionnaire, with many items depending upon the ability to see (e.g. orienting) or to move (e.g. self-help skills).

The most important result, however, is the strength of the responsiveness factor in both sets of data. The next step is to consider whether this is also reflected in subgroups within the population of people with profound handicap: i.e. are there responsive and unresponsive groups?

## 6.2 Cluster Analysis

Both sets of data were subjected to a cluster analysis. This procedure groups the subjects according to their similarity across all variables, with subjects that score the closest to each other forming separate groups. First, I performed a hierarchical cluster analysis. This initially places the subjects into two groups, then forms smaller groups out of these until no further separation is possible. The results of this for the questionnaire data is given in figure 6.35, in the form of a slightly simplified dendrogram showing separation to 10 groups, and the number of subjects in each.

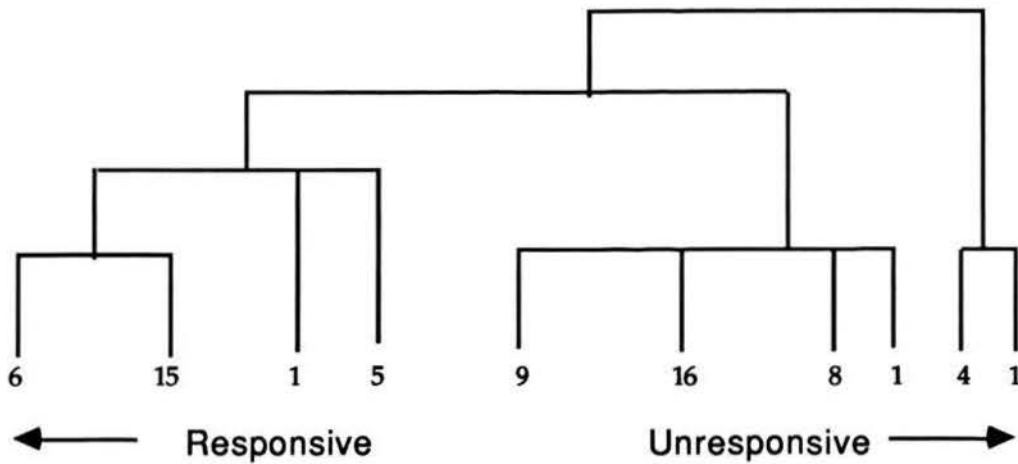


Fig. 6.35 Dendrogram of Clusters Based Upon Questionnaire Results

This cluster analysis formed a final total of 10 different groups consisting of one subject or more. When the characteristics of the subjects that make up the groups are examined, it is possible to discover what factors are important in the formation of groups. In this cluster analysis, responsiveness appears to be the single biggest factor. In fact, a distinct gradation in level of responsiveness can be seen across the final ten groups.

More detailed information can be obtained by specifying the number of final groups, and examining the scores of subjects in each group. I chose to divide the subjects into two groups using a simple cluster analysis procedure. This resulted in one group with 17 subjects, and another with 49. The differences between these groups are illustrated by a Mann-Whitney test of difference, which showed that the smaller group scored differently on the following:

<.001	<.01	<.05
Age (older)	Residence (hospital)	Spontaneous Learning (less)
Interest in Objects (less)	Phenobarbitone dose (more)	Orients to Event (less)
	Responsiveness (less)	Object in Mouth (less)
	Happy Expressions (less)	Acts on partner (less)
	Appropriate Smiling (less)	Initiates (less)
	Use of Words (more)	
	Laughter at Teasing (less)	
	Response to Anger (less)	
	Liking for People (less)	
	Liking for Music (less)	

The two groups which were extracted from the questionnaire results can be

thought of as responsive and unresponsive. This is true across a number of variables, and includes interest in objects and orientation. The unresponsive group also tended to be older.

Similar cluster analysis procedures were performed upon the video analysis data. Figure 6.36 (over) presents a dendrogram giving the results of the hierarchical cluster analysis, showing the number of subjects in the final 8 groups.

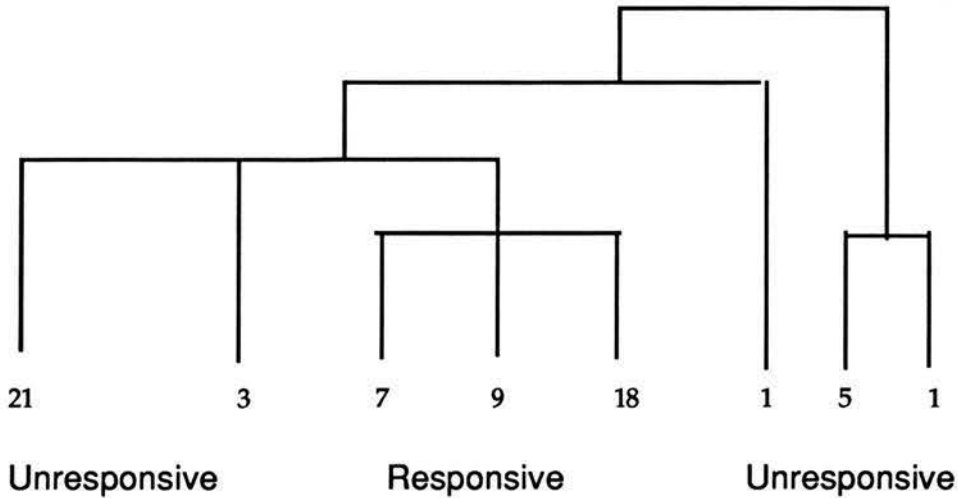


Fig. 6.36 Dendrogram of Clusters Based Upon Video Analysis Results

Once again, responsiveness appears to play a major role in group formation, though the unresponsive subjects were divided into two clusters of groups. One of these appeared to contain some subjects who scored very highly on interest in objects, and it is possible that this does indeed interfere with receptivity to carers so that they can be thought of as unresponsive.

A simple cluster analysis was also performed on the data from the video analysis, which divided the subjects into two groups: one with 13 subjects, and another with 53. The smaller group scored differently on the following:

<.001	<.01	<.05
Total Engagement (less)	Use of Facial Expression (less)	Residence (hospital)
Engages to Partner (less)	Happy Expressions (less)	Visual Handicap (more)
Engages Phys Cont (less)	Prec. Event: Phys. (less)	Auditory Handicap (more)
Engages Act Phys Cont (less)	Resists Engagement (more)	
No. of Engagements (more)	Resists Phys. Cont. (more)	
Sounds in Engagements (less)	Resists Act Phys Cont (more)	
	Interest in Objects (less)	
	Eye Contact (less)	
	Stereotypy (less)	
	Pushes (more)	
	Appropriate Smiling (less)	
	Sounds (less)	
	Prec Event/Res: Vocal (more)	
	Prec Event/Res: Food (more)	
	Prec Event: Unknown (more)	

Again, the two groups extracted can be thought of as (very) responsive and (very) unresponsive, and this is once more true across a number of variables. The groups differed on total engagement, engagement to the partner, and a variety of expressive characteristics. The unresponsive group tended to be resident in hospital, were more likely to have a sensory handicap, display stereotyped behaviours, give less eye contact and resist engagement more (which includes a predisposition to push the partner away).

Thus both sets of data produced groups divided according to responsiveness. When a detailed comparison is made of two groups formed by cluster analysis, in both cases one of them appears to be a small, extremely unresponsive group. When the actual membership of these small groups is examined, five of the subjects are the same. This suggests that even given the large differences in the method of data collection, some conclusions about subgroups within the population of people with profound handicap can be drawn: that their behavioural characteristics, whether observed directly or inferred from information given by carers, enable a division of the population into responsive and unresponsive groups.

The implications of this, and of the other results presented in this chapter, are discussed in the following chapter.

## CHAPTER 7. DISCUSSION

This thesis has examined, using video analysis and questionnaires, the characteristics of a group of representative individuals with profound handicap. In this final chapter, I will bring together the arguments proposed and the data collected in the previous chapters in an attempt to further clarify understanding of people with profound handicap.

### **1. A Summary of the Findings of this Thesis**

This research examined sixty six individuals with profound handicap, living at home or in hospitals, who had a wide range of ages and varying degrees of physical and visual handicaps. There were various aetiologies of handicap, including a large number 'unknown'. Half of the subjects were epileptic and many were receiving medication, most frequently an anti-epileptic. The important results of the questionnaire and video analysis studies are summarized below:

1. Carers reported that subjects are aware of their environment and generally responsive to attempts at interaction. Video analysis confirmed that the subjects consistently engage with and respond to their environment. They showed awareness on average for 69.5% of the session time, and were engaged with their partner for 63.6% of the time that the partner attempted engagement. All of the subjects used in this sample demonstrated some engagement to their partner. However, while they all terminated at least one engagement, only 19% of subjects initiated engagements during video sessions.

2. The carers report that people the subjects use a variety of expressive behaviours, including smiling and laughing, but that crying is very rare. The video analysis showed 86% used facial expressions during the sessions, usually smiling and laughing. Inappropriate smiling and laughing was also present, but much less frequent. Half of the subjects demonstrated some eye contact during sessions, though this was usually markedly different in amount and purpose from that seen in interaction between non-handicapped adults or mothers and infants.



3. Carers report a sense of humour in the subjects, especially a predisposition to laugh at unusual events such as accidents. This is seen in 50% of the subjects and may actually be triggered by the tones of voice used by the carers. Many of the subjects also seemed to be sensitive to the emotions of others.

4. Carers report that the subjects demonstrate a wide variety of preferences, including a liking for such activities as listening to particular pieces of music or traveling. On occasions, they may also refuse to comply with a carers wishes.

5. The subjects have moods which affect their behaviour. Carers considered these to be very important. A minority have sudden and severe mood swings. A third of the subjects actively resisted an attempt at interaction by the carer, and in some instances the resistance was quite violent.

6. Carers report that the majority of subjects have demonstrated spontaneous learning. During video analysis, 21% of subjects performed an act which indicated learning, such as a request for the carer to tickle their feet signalled by raising them towards the carers hands. Very few subjects demonstrated an understanding of cause-effect using objects.

7. The subjects produce a number of sounds, and a minority participate in turn-taking. In the filmed sessions, subjects showed a significant increase overall in the number of vocalizations during engagements.

8. Carers report some degree of sleep disturbance in nearly half of the subjects. Anecdotal evidence suggests that many of people with profound handicap may have problems with an internal 'body clock'. Other evidence shows that there is often fine control of the periodicity or rhythm of movements (Burford, 1989).

9. Carers report that many of the subjects have stereotyped or self-injurious behaviours, but they are seen in only a few subjects continuously. Video analysis showed stereotyped behaviours in 42% of subjects, self-injurious behaviours in only 6%.

10. The subjects responded to a number of different techniques or routine behaviours used by carers. All but one subject responded to physical contact during sessions (62% actually reached for and touched their partner), and most subjects

responded to use of objects and food.

11. Non-mobile subjects were not less responsive, but visually handicapped subjects were, and they tended to have more behaviour problems.

12. Two thirds of the subjects were receiving medication. These subjects were generally less aware, less interested in objects and more prone to inappropriate laughter. In particular, those receiving anti-epileptic drugs (52%) and phenobarbitone (12%) engaged for significantly less time. This was not true of those on benzodiazapine (19%) or psychiatric drugs (7%). It is not clear at present whether the differences in performance of the medication group is due to the effects of the medication, or the reason for the prescription (e.g. epilepsy).

13. Subjects resident at home (42%) scored higher on a wide range of ability and expressiveness variables, as did a subgroup made up of subjects that respond to tone of voice

14. Factor analysis of both sets of data reveal a responsiveness factor as the most important in explaining underlying variance in the results, explaining 22% of the variance of the questionnaire data and 14.3% of the video analysis data.

15. Cluster analysis using either set of data divides the subjects into 'responsive' and 'unresponsive' groups.

This summarizes the main findings of this thesis. The rest of this chapter will examine the relevance these findings have for the study and care of people with profound handicap. This discussion is divided into three topics: the psychology of profound mental handicap, the care of people with profound handicap, and the direction of future research.

## 2. The Psychology of Profound Mental Handicap

### *2.1 The Behavioural Characteristics of people with profound handicap*

This research has produced a wealth of information on the behaviour of people with profound handicap amounting to a comprehensive behavioural profile. Many of the findings of this research were expected: there were high rates of sensory and physical handicaps in the subjects; they had poor self-help skills; some showed stereotypy and self injury; and use of even the simplest of signs - a yes/no response - was absent in the vast majority, and unreliable in the others. This agrees with many descriptions of people with profound handicap in the literature. There were also some surprises in the results, including very high mean levels of engagement to carers and the presence of a wide range of communicative and expressive behaviours.

Making sense of this information is difficult. Chapter 4 argued that the sub-cortical structures responsible for the behavioural repertoire of young infants may be functioning in people with profound handicap, and that a comparison between these two groups may prove useful. The developmental framework outlined in that chapter, which paid particular attention to social aspects, has been valuable in determining the methods used to study behaviour and in selecting the behaviours which have been observed. It may also provide insights into ways of understanding them.

This chapter will continue to use a developmental approach in an attempt to reach a greater understanding of particular behaviours seen in people with profound handicap. It will also attempt to place these behaviours within a wider framework, based upon infant development, and determine which changes in behaviour are related to age. As a prelude to both, Table 7.1 summarizes the behaviours seen in the subjects during this research, and contrasts them with the similar behaviours of infants.

**Table 7.1 A Comparison of the Behaviour of Infants with People with Profound Handicap.**

BEHAVIOUR:	PMH:	INFANTS:
Engagement	Overall, high levels of engagement to environment - particularly the partner. Many techniques used by partners to obtain engagement are successful.	Engages with the environ - especially the mother - from the earliest times. Pre-wired to respond to human characteristics (e.g. shape of the human face). Mother uses a variety of successful techniques to establish contact (e.g. motherese, rocking) which are universal to humankind.
Activity, Awareness, Responsiveness & Orienting.	Most subjects were aware and responsive to the environment around them, though this was subject to mood and all went through regular periods of inactivity.	After birth, infants sleep for most of day but this proportion decreases with age. When awake, are aware and responsive to the environment from earliest times.
Initiation/ Termination	Few initiations of engagement, many terminations.	Takes active part in interactions, will initiate and terminate.
Facial Expression	A wide variety used by the subjects, a happy expression was most frequent.	Newborn can generate all facial expressions.
Appropriate Laughter & Smiling	Majority displayed smiling (80%) or laughing (36%) appropriate to context and preceding behaviour of carer.	Neonatal smiles responsive to stimuli from mother, stronger after 3w. Laughs at contingency at 4mo.
Inappropriate Laughter & Smiling	Seen in 36% of subjects, but duration very short.	Unsolicited smiling in infant during first few weeks, gradually disappears.
Crying	Very rare.	Infant cries from birth when distressed. Serves function of social signal.
Moods	All have mood swings. Usually, carers could ascertain the cause. Some subjects have severe, unexplained mood swings.	Infants have definite moods, related to physical well-being.
Emotional Sensitivity	According to carers, present in half of the subjects.	Infant responds appropriately to emotion of mother using facial expression at 2mo.
Laughter at Teasing, at Outbursts & Response to Anger	This sensitivity to the tone of voice of the carer was seen in around half of the subjects	Infants are sensitive to the prosodic features of speech (pitch, tone etc.)
Response to Individuals, Fear of Stranger & Strange Situation	Most respond to all people, but prefer one or two carers. A few subjects are very wary of strange situations or strange people. Some have no preferences for individual people or places at all.	Majority of infants form secure and balanced attachments with primary carer. Reflected in fear of strangers (1-4, 8-12m) and in reaction to strange environment. Some attachments can be over-dependant (infant too afraid of stranger) or too weak (no fear at all) in individual pairs.

Refusal to Obey Carer	Seen occasionally in most subjects; 35% resisted engagement, in some cases very violently.	Temper tantrums in infants from 4-8mos. In moderation, avoidance is sign of secure attachment (probably designed to initiate an approach from the mother).
Physical Contact	Most enjoy physical contact and 62% were seen to touch carer. A minority actively resist all physical contact.	Infants enjoy regular physical contact. A minority are known that do not and will resist being cuddled.
Eye Contact	Seen in 50%, but amount very small.	Eye contact from 4w, sustained, used to regulate interaction.
Imitation	Vocal imitation very rare. No evidence for imitation of gesture.	Imitation of simple facial gesture from birth.
Turn-taking	Some, occurs very rarely.	Turn-taking pattern in sucking from birth, in pre-speech in interactions at 4w. Infant & mum coordinated with precise timing.
Soundmaking	Most made simple sounds, and made more during engagements. Use of yes/no or (inappropriate) speech very rare.	Sounds from birth: cooing, 8w: babbling later, prespeech vocalizations, becoming complex. First words at 18mos.
Preferences	Preferences for people, music and travel seen in over half of the subjects. Some seem quite bizarre.	Infants show preference for mother and favourite games/toys.
Stereotopy/ Self-injury	Stereotopy seen in over 30% during video sessions, self-injury much rarer.	Some behaviours similar to stereotopy in infants (e.g. hand regard), and in minority, some self-hitting. Amount is very small, disappears with age.
Sleep Disorder	Seen at least occasionally in 35%. There may be problems with the 'body-clock'.	Sleep cycle of infants is different from that of adults (infants sleep more). Gradually changes with age.
Acts on Carer	Quite rare.	Infants take active role in controlling mothers actions (e.g. in interaction).
Interest in Objects	Most expressed some interest. In two cases this was extreme. Two other subjects had autistic tendencies.	Interest in objects from birth, but behaviour towards them changes with age: 1-4mos: mouths; 4-8: grasps; 8-12: shakes, rotates; 12-18: builds blocks; 18-24: symbolic play.
Mouthing Objects	31% of subjects were reported to mouth objects, but only 4 were filmed.	Mouthing objects is typical between 1-4mos.
Learning	Spontaneous learning in most subjects.	Infants able to learn contingency 4-8mos. Recognise individuals etc. much earlier.
Cause-Effect	Very rare. Seen in some, in varying degrees.	Achieved by 12-18mos.

Although the individual differences in the subjects make it difficult to make direct comparisons and draw firm conclusions, some general comments may be made concerning this table.

The table clearly shows that many of the behaviours with a sub-cortical basis which were described in Chapter 4 (e.g. facial expression and emotional sensitivity) are represented in the behavioural repertoire of people with profound handicap. This table also suggests that there are several behaviours of people with profound handicap for which infant development offers a useful source of information which may help us to understand them better. Here, I will attempt an overview of these behaviours.

*Engagement and awareness:* Figures for the amount of engagement in the subjects is hard to compare directly with infants. Generally, the subjects do not appear to play as active a role in interactions as do infants (initiations, for example, are comparatively rare), but high levels of awareness and engagement were obtained. This is covered in more detail in section 2.2.

*Emotions and expressive behaviours:* This research found a rich variety of social, affective behaviours in people with profound handicap. In the majority of subjects the emotions were found to be an important factor in day-to-day behaviour (dealt with separately in section 2.3). Moods can affect all aspects of the subject's responsiveness. In infants, moods are tied to a physical cause such as hunger, constipation or comfort, and the same appears to be true of people with profound handicap, although a minority experience sudden, severe, and unexplained mood swings, possibly as a result of brain damage.

Most subjects regularly used a number of expressive behaviours and essentially these are similar to those observed in infants. It is also important to note their reactive nature. Happy expressions were displayed in happy situations, for example, and appropriate smiling and laughter was much more frequent than inappropriate smiling and laughter. Crying was very rare in the subjects, and the reason for this is unknown. Two carers remembered adult subjects crying when a young child, however, so it may be linked to changes in age. In infants crying is used as a subtle and varied signal of distress and undergoes considerable development. There is some evidence that there is a similar refinement of different types of crying, and that they are used for similar signalling purposes, in some institutionalized people with profound handicap (Fraser and Ozols, 1981).



*Sensitivity to emotions:* Many of the subjects seemed to be sensitive to the emotions of others. Sometimes this involved no more than picking up anger by the tone of the carers voice. Occasionally there appeared to be a substantial change in behaviour provoked by a change in the carers mood for which the subject appeared to be sensitive. This sensitivity is hard to establish conclusively, but it might reasonably be predicted as infants have been shown to respond to changes in their mothers facial expression at only 2 months (Murray and Trevarthen, 1985). If this ability to engage at an emotional level exists, it can be seen as part of a general sensitivity to the environment, of a form particularly applicable to people.

*Aspects of attachment:* The way people with profound handicap behave towards other people is clearly of special importance. In Chapter 4 the ways in which an infant's behaviour differs when interacting with a person and when attending to an object was described. It seems to be essentially the same in people with profound handicap: the overwhelming impression is that all of the subjects reacted to people in qualitatively different ways from objects.

Infants form close relationships or attachments with their mother from the earliest times (Bowlby, 1969) . The strength of such a relationship is indicated by attachment behaviours such as signaling (crying, calling), approaching (reaching, creeping), or clinging. In this research, the behaviour of the subjects towards their carers was examined for signs of attachment. All subjects seemed to have preferences for some people, and all showed recognition for certain individuals, but indications of a well formed, balanced attachment were not common. Some subjects showed no attachment at all, and would "walk off with anyone". A minority (all home subjects) responded only to the mother. They may correspond to the infants found by Ainsworth et al (Ainsworth, Blehar, Waters and Wall, 1978) to have a disorganized and insecure attachment to the mother.

Strength of attachment was also examined through questions concerning fear of strangers and fear of a strange situation, which are important in studies of infant attachment. This behaviour can appear in infants by six weeks, but is heightened at around 8-12 months. In infants, the initial fear is a fairly elementary reaction founded on dependence on the mother by the infant, and demonstrating the bonding between them. It becomes heightened at the end of the first year after a mother-infant dyad have developed games and routines. The stranger does not know these, and the infant finds the situation of confrontation with the stranger upsetting. In people with profound

handicap, reactions to strangers is more likely to be of the earlier form of the behaviour: they are less likely to develop routines with a carer and less likely to be sensitive to changes in them.

In infant research, these behaviours are often examined using the 'Ainsworth situation' (Ainsworth, Blehar, Waters and Wall, 1978), a procedure for assessing attachment in 12-18 month-old infants which involves placing the infant in a novel room, exposing him to an unfamiliar stranger, and separating him briefly from his mother and then re-uniting them. The reactions of the infant to these situations can be used to assess the organization of attachment behaviour. Typically, there are wide individual differences, but well adjusted infants will show a clear preference for interacting with the mother and will seek contact on re-union, but will also explore new situations with ease. Less secure infants will be afraid of new situations, wary of strangers and will refuse to interact with the mother on her return.

Although the Ainsworth situation was not used in this research, reactions to similar situations were described by carers. Fear of strangers was not reported very often, but around 30% of the subjects were thought to show it occasionally. Usually this manifested itself as a general quietness and two subjects did this very frequently. Two subjects showed a heightened fear of strangers and abnormally strong attachment (which was manifested in a desire to keep the carer in sight at all times). Many showed no such fear and no preference for the mother on her return.

In four cases, subjects had ignored mothers when they visited their school. At first this seems to suggest that no attachment exists, but carers reported that the avoidance was only temporary. This behaviour may therefore be compared to the avoidance reaction of infants re-united with the mother following separation (Main and Weston, 1982). This is important evidence for attachment between people with profound handicap and their mothers.

*Refusal to comply with the carer:* An interesting behaviour observed in the subjects is the refusal to comply with the carers wishes. Sometimes this behaviour was excessive and occasionally, when a subject was resisting engagement, the movements of protest and avoidance could become quite violent. Traditional views of people with profound handicap see them as passive, which this resistant behaviour is not. Alternatively, we could see the behaviour as disturbed. However, we could also assume that it may be quite justifiable to resist an engagement if it is not wanted. Here,

infant research offers some information: at around 4-8 months, the infant begins to develop rivalry, stubbornness, deceit and temper tantrums. These are all part of the development of personality and our judgements of this kind of behaviour should not be prejudiced by the requirements of care, which encourages compliant responses. Interestingly, it has been argued that such active avoidance on the part of infants is a sign of a secure and well adjusted attachment with a carer (Bowlby, 1969). Thus, the purpose of a temper tantrum is eventually to stimulate an approach and comfort behaviour from the carer. In view of the frequency and severity of the resistance in most of the subjects, however, this is not a likely explanation for the behaviour, but may offer insight into individual cases. Refusals were more prevalent in younger subjects.

*Physical contact:* Most subjects enjoyed physical contact, and 62% touched their carer at some point during the video sessions. Some subjects dislike physical contact, however, and some may even scratch carers or push them away. Given the amount of passive physical contact inflicted daily on a physically handicapped hospital resident, it seems possible that some build up an aversion. There are alternative explanations, however. A considerable minority of normal infants appear to be antagonistic to all physical contact from the mother and are found "actively to resist and protest at being embraced, hugged and held tight" (Shaffer, 1977). These 'non-cuddlers' are more active, restless and intolerant of physical restraints such as being dressed or tucked in bed. The reason for this behaviour is obscure, but it is evident from the first few weeks and it does not appear to stem from the way the mother handles the baby. The later development of these infants does not seem to be affected, and they still form an attachment with the mother, preferring to keep her in visual rather than physical contact. It may be that a similar process is occurring in some people with profound handicap, or it may be that these infants are making a similar rejection of the close physical contact involved in caring for someone unable to feed, toilet or dress themselves. Another possibility is that this behaviour represents a form of autistic behaviour, other aspects of which have been noted in people with profound handicap in the previous chapter.

*Eye Contact:* Eye contact with the carer was seen in many subjects, though the amount was typically very small. It is difficult to compare this directly with eye contact in infants or the general population. During interaction, participants typically look at each other for 25% to 75% of the time, for periods of 1 to 10 seconds (Argyle, 1972). Mutual gaze or eye contact is somewhat shorter. There are many individual differences

even in the normal population, but generally the figure for eye contact in the subjects is considerably lower. More significant are the differences in the way eye contact is used. In normal interactions, it has an important regulatory function and its absence - particularly in an infant during the first year - creates an impression of unresponsiveness and coldness (Exline, 1974). In the subjects, eye contact appeared to be infrequent, unreliable and of short duration in most cases, and it rarely appears to be used as a regulator of interaction.

*Imitation:* There was no evidence of imitation of simple gesture in the subjects. This is surprising, as imitation of simple facial gesture has been seen in newborns (e.g. Meltzoff and Moore, 1977). There are no obvious reasons for the absence of this ability in people with profound handicap, but I suggest that it may be linked to the absence of self-recognition demonstrated by Pechacek et al (Pechacek, Bell, Cleland, Baum and Boyle, 1974) and Harris (1977).

*Turn-taking:* Although some subjects did seem to show alternation of expressions with a partner, it is hard to be certain of the occurrence of controlled turn-taking and it is certainly nowhere near as common as it is in the protoconversational behaviour of infants. Turn-taking appears to be a very basic ability, four-week-old infants demonstrating the capacity for conversation-like turn-taking in their non-nutritive sucking. It is extremely important in helping to regulate interactions with a partner. The reason for the absence of this ability in people with profound handicap is unknown, especially as they appear to have some control over the timing of movements (Burford, 1989). It may be because of the generally reduced attention span typical of people with profound handicap. However, turn-taking is completely dependant on the sensitive responses of the partner, and it is possible that in interaction some carers do not allow their partner time to respond (Ware and Evans, 1986). This ability may therefore be more prevalent than it appears.

*Soundmaking:* The sounds used by subjects tended to be very basic, monosyllabic and repetitive, though use of sounds did appear to increase during engagements. Infants make cooing sounds from birth, and begin babbling at 8 weeks. Gradually, the sounds become more complex and more like speech, with the first words appearing at 18 months. The majority of the sounds made by the subjects in this research resembled the sounds of younger infants, which are under the control of subcortical regions (Ploog, 1979). No subjects used appropriate speech, although a very small minority possessed the ability to produced speech-like sounds. Some of

these subjects imitated individual words, but would also produce nonsense words. This tends to reinforce the proposition that the brain structures responsible for the development of language are damaged in people with profound handicap.

*Expressed preferences:* It is interesting to consider whether the preferences for human features seen in infants are also seen in people with profound handicap. Many subjects appeared to be sensitive to unusual sounds or movements made by people. Most certainly seemed to enjoy human company. Several subjects had clearly defined preferences for types of music and sometimes these were very specific. It may well be that the crucial factor in the preference is the prosodic characteristics of the music. In fact, one subject would only listen to recordings made by Frank Sinatra when he was young, even when offered recordings of the same songs made by the old Frank Sinatra. Clearly, the tone and pitch of the singing voice is important. In addition, nursery rhymes were very popular amongst the subjects, as were simple pop songs and short television theme tunes, indicating a preference for simple rhythms.

Other common preferences included a liking for traveling in cars. This is most likely related to the proprioceptive experience, and many subjects also showed a preference for being bounced and rocked by carers. This is paralleled by a similar preference in infants.

*Behaviour problems:* Stereotopy was fairly common, self-injury much rarer. It does not seem convincing to suggest that these have their roots in the similar behaviours observed in some infants for a short time. Alternative explanations include brain damage and a response to boredom. In this research, stereotyped behaviour was seen in some very stimulating situations, but was also often reactive to events in the environment (reducing after the introduction of a toy, for example). These observations support both theories, and suggest a strong connection to changes in the environment.

*Sleeping disorders:* There were high rates of sleeping disorders in the subjects, which may infer a malfunction in an internal regulatory mechanism (perhaps caused by an inability to reset the 'biological clock' using external sources). The sleep cycle of infants changes with age as the amount of time spent sleeping decreases, but the relevance of this for people with profound handicap is unclear as yet.



*Directive acts on carer:* This behaviour - requesting a specific, desired action by a carer - was not common in the subjects, but was present in some. The complexity involved varied, however. Some subjects, for example, would take and direct the carers hand towards a foot to be tickled, but others merely raised their foot towards the carer. Infants will take an adults hand and direct them towards an object from around the end of the first year. In interactions, however, they play an active part in controlling the behaviours of the partner from the first month.

*Interest in objects:* This behaviour, which many of the subjects demonstrated, is not easy to identify with a particular phase of infant development since infants are interested in objects from the first month. It is more revealing to note what is done with the object: subjects did not use fantasy play (e.g. pretending to drink from a cup or dressing up a doll), which infants may demonstrate after 12-18 months, nor did they imitate a carer's specific use of an object, seen in normal development around 18-24 months. Some subjects did occasionally seem to present an object to a carer. Piaget believed this is an action designed to instigate social action, not appearing in infants until 12-18 months. However, an infant younger than 12 months can hold an object out towards a person as if offering it, just as they can point to objects while engaging in communication with a partner. Most of the actions towards objects that were made by the subjects are characteristic of lower levels of development. Typically, they manipulated an object in their hands, and occasionally shaken or dropped it, techniques used by 4 to 8-month-old infants. Even more revealing, a significant number of subjects also regularly mouthed objects, a behaviour typical of 1-4 month old infants.

*Cognition and knowledge of cause and effect:* Some evidence for the cognitive abilities of people with profound handicap were obtained in this research, most notably in the examples of spontaneous learning, dealt with separately in a later section. Piagetian tasks, which have been used with people with profound handicap many times, were not used, though evidence was accumulated of behaviours demonstrating some of the same cognitive capacities. Knowledge of cause and effect was examined by asking carers for examples of correct use of a switch or wind up toy, and replies were often confirmed by observation. Subjects demonstrated mixed abilities in this area: the majority (47) made no attempt at operating a toy; others gave toys to an adult to be activated (which Piaget believed represented the ability of children aged between 12 to 18 months); some were able to press a simple switch; and very few subjects (2) could also wind up the toy without assistance (behaviour not



seen until 18 to 24 months in children). This presents a curious paradox: even those subjects demonstrating abilities which are typical of older children (i.e. toddlers rather than infants) had no language, no self-help skills and severe problems in training.

The absence of language is very perplexing, since language and symbolic thought is supposed to dominate the thought processes of children towards the end of their second year. One subject who demonstrated the ability to activate and wind up a musical toy, for example, has no expressive language at all, and extremely limited receptive language. Yet his understanding of objects seems on occasion to be quite advanced. This subject actually spends all of his waking life manipulating objects and it is tempting to wonder whether practice has resulted in an advance in this particular area of development, though according to Piagetian theory such an advance should not happen independently of the others. Alternatively, perhaps he has developed an internal approximation of symbolic thought which is not expressed to the outside world. It is hard to get any closer to finding the answers to these questions, particularly when such behaviours are so variable and unpredictable in people with profound handicap that they may not be performed during a formal assessment.

This overview has described a number of interesting behaviours seen in people with profound handicap, and it has shown that information from studies of infants may contribute much to our understanding of them. The next part of this section will attempt to relate these behaviours to each other, and place them in a hierarchical scale according to their appearance in development.

*The development of behaviours in people with profound handicap:* An important step in understanding the behaviours of people with profound handicap would be to place all such behaviour on a continuum based upon normal development. There are two obstacles in achieving this: the differences between people with profound handicap and infants, and the differences between individuals with profound handicap themselves.

This chapter has so far emphasised the similarity between people with profound handicap and infants, but it is vitally important to recognize the differences. Some are obvious, others can be quite subtle. Amongst the more obvious are the presence of additional handicaps such as blindness, immobility and epilepsy. There are also many differences in behaviour: the overview presented above describes several behaviours

of infants which are absent or distorted in people with profound handicap. Turn-taking and imitation are absent, for example, and a well balanced attachment with a primary carer is missing in most institutionalized subjects. Perhaps the most important difference, however, is that infants are developing very fast, whereas people with profound handicap are developing very slowly, or not at all. In addition, it seems that the development of behaviours that does occur in people with profound handicap is different from normal development and raises serious problems. Some individual subjects appear to possess cognitive and communicative abilities which are far in advance of their other abilities. Thus, one subject possessed knowledge of cause and effect which, according to cognitive developmental theory, is theoretically impossible given the intellectual deficits of profound mental handicap. Such a discrepancy is not normally found in infant development, though it has echoes in the early development of imitation and social behaviours which are not explained by cognitive theories of development.

These problems are multiplied when the differences in the development of individuals is considered. Amongst people with profound handicap there are vast differences in behaviour which make generalizations impossible: Some subjects may demonstrate a particularly advanced knowledge of cause and effect, others may have severe behaviour problems, still others may show a strong fear of strangers, whilst other subjects may show none of these behaviours.

One can offer several explanations for these individual differences. It is possible that all subjects might retain an ability, but many may not show it. Alternatively, there may be real differences in the stages of development attained in particular areas of behaviour by individual subjects or groups of subjects, who are nevertheless all functioning at the level of profound mental handicap. The second explanation is the more likely, but still leaves many unanswered questions: will all subjects attain the same level of development in time? Is there a limit to the development that people with profound handicap can achieve? Why have some subjects progressed further in some areas at a given age than others? Is this due to different patterns of brain damage or different opportunities offered by the environment? Why are some of these developments so hard to reconcile with traditional theories of development? The answers to these questions remain elusive.

The problems raised here suggest that it is impossible to fully understand the development of behaviour in people with profound handicap by referring to normal

development. Within the narrow field of cognitive development, however, some progress has been made. The development of children with profound handicap has been mapped by several studies using Piagetian tests (see Chapter 4). The results of these confirm both of the observations made above: that development of people with profound handicap differs widely between individuals, and from the normal population. The studies show that even in the same individual development is not stable across different domains: children with profound handicap progress at different rates in different areas of development. There thus appears to be many significant deviations from the pattern of normal development.

My observations were not intended to test cognitive abilities, but show a similar phenomenon in the development of social behaviours: that their development in people with profound handicap is different from normal development. Thus, subjects demonstrating fear of strangers, for example, simply do not demonstrate other abilities representative of the appropriate stage of normal development. This research has produced much information on the presence of social behaviours in people with profound handicap. Although it is possible to observe a discrepancy with normal development, it is difficult to make any progress in detecting a systematic pattern with which to form an alternative scale of development.

I have made a simple attempt at this kind of interpretation of the results, however, by comparing the mean ages of subjects that demonstrate particular behaviours with the mean ages of those that do not, in order to ascertain the presence of developmental trends. The behaviours chosen were those for which we have an understanding and age range from studies of normal development.

The results of this are given in table 7.2 which uses information from the questionnaires to show the prevalence of several important behaviours. It shows the number of subjects showing and not showing a behaviour, and gives mean ages for these two groups. A third group consists of those subjects showing a behaviour frequently. The table further divides the subjects into those resident in hospital and those resident at home, because of the large age differences associated with place of residence. The table therefore allows a crude estimate of whether a behaviour increases or decreases with age. The direction of any such trend is given in the fourth column.

Behaviour:	HOSPITAL		HOME		Change with Age
	Mean Age	No.	Mean Age	No.	
Fear of Strangers:					
Present often	21.6	(3)	12	(5)	
Present	21	(6)	13.7	(13)	<i>decrease</i>
Absent	27.6	(32)	18.6	(15)	
Object in Mouth:					
Present often	21.1	(7)	13.6	(8)	
Present	21.9	(12)	14	(13)	<i>decrease</i>
Absent	28.7	(26)	18.3	(15)	
Interest in Objects:					
Present often	18.5	(9)	12.5	(12)	
Present	23.3	(22)	15.1	(27)	<i>decrease</i>
Absent	31	(16)	49	(1)	
Fear of Situations:					
Present often	24.3	(3)	12.7	(6)	
Present	28.4	(7)	12.4	(14)	<i>decrease</i>
Absent	26.1	(31)	20.2	(14)	
Self-Help Skills :					
Present to large degree	28	(2)	20	(1)	
Present	26	(19)	17.4	(17)	<i>increase</i>
Absent	27	(19)	14.6	(11)	

**Table 7.2 The Development of Behaviours with Age: Based Upon Results of Questionnaire Analysis.**

*Mean Age of All Subjects: 22.2 years*

Although sample size is small, the table does allow some interesting observations. Subjects showing some behaviours, such as fear of strangers, fear of situations and mouthing objects, are generally younger than those that do not, both in those resident in hospital and those at home, and the trend is for the behaviour to be more frequent in younger subjects. The opposite trend is seen in self-help skills, which increases with age. There is, then, a suggestion that the older subjects may have grown out of some responses.

This analysis of the results suggests that there is some pattern in the behaviours of people with profound handicap and that some of these behaviours develop with age. Some behaviours, such as self-help skills, seem to increase with age, whilst others, such as fear of strangers and mouthing objects (all of which are more typical of younger infants), tend to decrease with age.

A little supporting evidence comes from a similar analysis of the video results shown in Table 7.3. This table suggests that tendency to put objects in the mouth and eye contact are more frequent in younger subjects. In contrast stereotopy, for example, is more common in older subjects. The time sample used in the analysis is too small to draw firm conclusions, however.

<u>Behaviour:</u>	<u>HOSPITAL</u>		<u>HOME</u>		<u>Change with Age</u>
	<u>Mean Age</u>	<u>No.</u>	<u>Mean Age</u>	<u>No.</u>	
Object in Mouth:					
Present	24	(1)	13.7	(3)	
Absent	25.3	(26)	15.2	(15)	<i>decrease</i>
Eye Contact:					
Present	25.3	(11)	15.4	(23)	
Absent	27	(27)	20.4	(5)	<i>decrease</i>
Interest in Objects:					
Present	23.3	(24)	14.9	(18)	
Absent	40.6	(3)	0	(0)	
	<i>decrease?</i>				
Stereotopy :					
Present	30	(18)	16.9	(10)	
Absent	23.4	(20)	16	(18)	
	<i>increase?</i>				

Table 7.3 The Development of Behaviours with Age: Based Upon Results of Video Analysis.

*Mean Age of All Subjects: 22.2 years*

This breakdown of the results is a start at placing the behaviours of people with profound handicap in relation to each other and into a developmental framework. Some behaviours which are typical of younger infants, such as object sucking, appear to be more common in younger subjects, whereas self-help skills are refined with age. How much the pattern of behaviours in each individual will change with age cannot be known for sure without a longitudinal study, but a naturally occurring development in the behaviour of people with profound handicap is suggested by these results. However, the large differences between individuals may make it impossible to draw up a firm scale of development in people with profound handicap.

This represents a beginning in achieving a greater understanding of the behaviours of people with profound handicap by the use of a developmental framework. A wide variety have been described, and an age related development has been outlined. A common thread running through these behaviours is a predisposition



for people with profound handicap to react to or attempt to change the behaviour of persons around them. This ranged in practice from reacting positively to a carers attempts at engagement to actively avoiding their advances. This research has found, much as developmental research has found with infants, that the majority of people with profound handicap are not passive, but take an active role in changing the environment to suit them, or in making their feelings known. These findings may lead us to re-assess the potentialities of people with profound handicap for taking a controlling influence in their environment.

## *2.2 The Engagement of people with profound handicap*

The findings of this research suggest that people with profound handicap are sensitive to their environment and capable of interacting with their carers. Overall, unexpectedly high levels of engagement were obtained. Equally astonishing was the observation that all subjects engaged to their carer for at least part of the session time. In the light of this finding, the quotation used in the introduction which described people with profound handicap as 'vegetative' with 'no awareness of his surroundings', clearly has no basis in reality. There is no justification for continued belief in such an unfounded generalization.

If the total duration of engagement between subject and partner is expressed as a percentage of the total session time, the mean figure is 55.8%. This is very much greater than figures obtained in previous studies of interaction such as that of Wright et al (1974), who found interactions accounted for only 7% of the observation time. The reason for such a large difference is not hard to find. The present study looked at individuals interacting with a single, familiar carer and used video techniques which allowed for a fine grain level of analysis. Traditionally, studies of interactions with people with profound handicap (including Wright et al, 1974) have looked at a number of carers whilst they interact with groups, typically in a ward or classroom situation, and typically using time sampling to measure behaviour. The two approaches are complementary, but the second does not study the potential for interaction in people with profound handicap, it merely estimates the rates of interaction observed in a less than ideal situation. Unless people with profound handicap are looked at in situations which facilitate their limited and unstable abilities to communicate, a misleading impression of what they can do will surely result.



This study has also examined the content of this interaction in far greater detail than other studies have done. It has revealed a range of behaviours used by the carer to establish and maintain an interaction, and a range of responses in people with profound handicap. Carers used a variety of techniques in interacting with the subjects. Some used food as a reliable, direct method of gaining attention (though this was not always effective, showing that other motives may overrule the desire for food in people with profound handicap). More successful in terms of the richness of the ensuing interaction were the presentation of an object and, especially, the use of active physical contact. Although this research did not concentrate on the techniques used by the carers (this is the topic of the 'Moving in Sympathy' research), it is worth noting the main types of active physical contact used by the carers during the sessions. These included stroking, patting, rubbing and cuddling, as well as more vigorous games such as rocking and swinging. Carers also used motherese and 'baby-talk' vocalizations extensively when communicating with the subjects. These behaviours are also typical of the way mothers communicate with their infants in their first two years. Some carers intersperse these activities with nursery rhyme games, and these were often very successful in gaining attention, though the subjects on which they were successfully employed were sometimes amongst the least advanced developmentally. Such rhymes are a feature of the mother's behaviour when the infant reaches 3 to 6 months of age.

As we have seen, the similarity in the behaviours of mothers and carers is paralleled by other similarities between the behaviours of people with profound handicap and those of young infants. A variety of expressive emotional and communicative behaviours in the subjects closely resemble those of infants. Surprisingly, there is evidence of sustained eye contact in some people with profound handicap (especially in Rett's Syndrome (Kerr, 1986)). Facial expressions are common and, although happy and sad expressions are the most frequent, carers could often also describe instances of angry and frightened expressions. Furthermore, many people with profound handicap demonstrate a discriminating sense of humour, which has some extremely interesting aspects.

### *2.3 The Emotions and Humour of people with profound handicap*

The emotions of people with profound handicap are likely to play a central role in our understanding of their behaviour. The first indication that I had of how

important they are came with the realization that many of people with profound handicap have a functioning sense of humour, and that they will laugh at specific events (as described in Chapter 6). These events include forms of stimulation that might be expected to produce humour, such as tickling, physical play or rocking (which may cause vestibular stimulation), eating food, or water play. More remarkable, however, was a predisposition amongst half of the subjects to laugh at a variety of events which were at first sight unrelated to each other, and where the humorous content was not immediately obvious. These events included: others having accidents; one person telling off another; someone sneezing; and a carer teasing vocally by exaggerating the vowels in speech. Some subjects even laughed at the punchlines of jokes, the verbal content of which they certainly could not have understood.

I believe that one way to link these events together is to look at the vocal (and possibly the gestural and postural) characteristics of the expressions of the other person who instigates the laugh: in every case the expressions are unusual. In some cases the voice may not be the the main carrier of information about an unusual set of expressions or accident - for example in laughing at someone falling over there may also be a visual component - but the results suggest that awareness of unusual prosody or voice quality may be worth further investigation.

This issue is, I think, a vitally important one. Carers certainly value this evidence of a sense of humour extremely highly, and were delighted that someone had actually asked them about it. It has not, to my knowledge, been commented upon before, but a social, discriminating sense of humour in people with profound handicap represents the presence of a unique human ability, which obviously has profound resonances for their carers.

Unfortunately, it was extremely difficult to examine this ability in any further detail. As lack of time precluded a controlled experiment in which I could replicate the behaviour of carers which had stimulated laughter in the past, I opted for a small scale study which attempted to define the range and frequency of humorous responses in people with profound handicap.

*Events provoking laughter through the day - a diary study:* This study examined the day-by-day emotional behaviour of a small group of subjects. It described their general mood swings, the frequency of periods of laughter, and the events which

preceded each of them. Data was collected in diaries kept by the parents of four subjects. These diaries contained thorough descriptions of the events of each day and of the behaviour of the subject.

From the descriptions in the diaries, incidents where subjects laughed or smiled at particular events could be identified and classified. In total, the diaries described 195 such incidents. They therefore occurred, on average, 1.6 times a day in each subject. There were no significant differences between the number of incidents which occurred during the day (91) and the evening (104). Amongst the most popular of the events which preceded bouts of laughter were 'body noises' such as sneezing, which precipitated 28 outbursts of laughter, and vocal teasing by a carer, which precipitated 29. The subjects frequently joined in with the laughter of others (reported 20 times). Accidents befalling the carer also caused laughter in all four subjects (occurring a total of 10 times), and in one case the subject seems to have deliberately caused someone to trip up by stretching out a leg!

All subjects experienced very short changes in mood during the course of a day, and a cause for most of these (epileptic activity or hunger, for example) could be determined by the parents. Looking at the overall mood during day and evening, all four subjects experienced mood swings fairly often over the course of the month, and some changes were quite dramatic. On 17 occasions, this change occurred during the course of a single day. In general, however, the subjects spent 70.5% of the time in a happy or very happy mood, 7.5% in an unhappy mood, and 22% in a quiet, unresponsive mood.

These diaries are very revealing. They show that the emotions play a major part in the day-to-day behaviour of these children. They respond in different ways according to the different environments they are in, and the way they are feeling. They are sensitive to what is going on around them and reveal this sensitivity in their behaviour. They are also sensitive to the tone of voice of carers, to unusual voices and to unusual movements. Interestingly, in some cases the diaries also seem to have provided new insight for the parents, making them look again at the emotions of their children and realize how active they are, and how much the behaviour of the family affects them.

A summary of one of the diaries is presented in Table 7.4 (over).

MON		TUE		WED		THUR		FRI		SAT		SUN	
No.													
DAY	Q: bn	VH: bn p l v/um at	H: u ts smile: m	H: ts n smile: m	H: v	H/U: ts ts c/at	H: ts ts	18					
	H: v bn v v l ts/p												
EVE	H: v bn v v l ts/p	VH: ts at at v ts	H: t/ts	H: bn t a	H: p	H: p a/l bn/ts	H: ts v/um ts/at	22					
DAY	Q:	H: p m v	H: bn ts smile: m	Q: smile:m	H: a p/v	U: ts smile:p cried	H: ts ts bn	14					
	Q/H: v to p a p												
EVE	Q/H: v to p a p	H: bn v bn	H: p	Q: to t	Q: a	H: p v ts l bn	H:	17					
DAY	H: bn p ts/m	H: smile: p	H: v bn	H: v	H: smile:p	H: smile:c	Q:	9					
	H: v p												
EVE	H: v p	H: bn p	H: v	H: at ts	H: ts	H: bn p/ts	Q:	11					
DAY	H:	U:	H: ts	H: v/m	Q:	U:	Q/H: m ts ill	4					
	H: bn												
EVE	H: bn	U: at	H:	H: ts	H: p a	U:	Q/H: v/um ill	6					
DAY	Q/H: bn	U: bn at	Q/H: at	15		9		16		11			
EVE	H: c ts/p	H: ts m/p	Q/H:	4		5							

KEY: PRECEDING EVENT TO LAUGHTER =

a Accident

ts Teasing (vocal)

bn Body Noise

m Music

uv Unusual Voice

t Tickling

c Car Journey

l Laughter of Others

at Gen. Atmosphere

to Telling Off

n Noise

p Playing/Movement

u Unknown

um Unusual Movement

KEY: PRECEDING EVENT TO LAUGHTER =

a Accident	l Laughter of Others
ts Teasing (vocal)	at Gen. Atmosphere
bn Body Noise	to Telling Off
m Music	n Noise
uv Unusual Voice	p Playing/Movement
t Tickling	u Unknown
c Car Journey	um Unusual Movement

Table 7.4. Diary Study: Moods and Laughter in One Month.

Moods: VH= very happy; H= happy; Q= quiet; U= unhappy.

This diary classifies each occasion where the subject laughed in terms of the preceding event (such as body noises (sneezing etc.), unusual voice (breathless etc.), and the laughter of others). It also gives the general mood of the subject during the day. (happy, unhappy, and quiet). The table covers one month, with each day being dividing into day and evening. Event totals are given for each column (day of the week) and row (evening and day). The preceding event is calculated from information given in the diary. A cause can never be completely positively identified, but it can be identified with reasonable certainty. The information presented in the table was collected by parents, teachers and the taxi driver who drove the subject to and from school, and thus covers 24 hours a day.

From the table, it can be seen that this subject had bouts of appropriate laughter almost every day, although there was considerable variation. On one day, for example, the subject was in a quiet mood and there was no laughter at all; on another, the subject was in a very happy mood and ten individual bouts of laughter were recorded. What cannot be seen from these figures alone, but is clear in the descriptions in the diary, is the fact that this subject plays an active part in the social life of the family. The diary shows the subject to be very responsive to people and events around him, though the subject seemed to be less active at school, during the day. One possible explanation for this is that the teacher was too busy to record all of the behaviours of the subject, but it could also be that the subject was actually quieter at school, and more inhibited in a group. The most important finding of the diary, however, is that it confirms the role of unusual vocalizations, and possibly unusual movements, in stimulating humour. It must be stressed that this subject, though often aware, responsive and sociable, nevertheless has a profound handicap.

Many people with profound handicap, then, have an active emotional system, and will laugh at a certain range of events. What is unclear is why they find such events funny.

*Theories of laughter:* There are three main theories of humour: superiority, relief, and incongruity (reviewed comprehensively by Berlyne, 1969, and more recently by Morreall, 1983). The superiority theory, first expounded by Plato in *The Republic* and Aristotle in *Rhetoric*, and later revived by Hobbes (1840), sees laughter as an expression of a person's superior adaptation to a situation. If someone slips on a banana skin, for example, others laugh because they feel superior to that person. This may have evolved from the expressions of ridicule and relief made after the defeat of a



rival. This is plausible, but the theory does not explain tickling, self-deprecating humour, or nonsense humour.

The relief theory was proposed by Spencer (1911), who believed that laughter is the release of a build up of nervous energy. Freud developed this idea (1976), seeing laughter as the release of 'superfluous energy', originally intended to suppress an emotion. Thus obscene jokes release energy originally meant for suppressing the forbidden thoughts and feelings with which they deal. This theory implies that we are always emotionally involved with what we laugh at, however, which is not true. Also, laughter does not always consist of a large build up of energy followed by a large release, but can be a gradual process (such as chuckling).

The incongruity theory, first proposed by Kant (1892) and Schopenhauer (1964), sees laughter as resulting from situations in which expectations are upset and what follows is incongruous. A large, heavily built wrestler speaking in a very high voice is, for example, likely to be perceived as funny. This laughter involves the evaluation of an event, and an expectation of what will happen. In this case, large wrestlers are normally associated with deep voices. This theory does not explain why many incongruous events are not perceived as funny, however, nor does it explain tickling.

Do any of these theories offer a way of explaining the behaviour of people with profound handicap subjects? Laughing at accidents befalling others, perhaps the most striking of the humorous responses of the subjects, has long been recognized in theories of humour. Called variously 'Lucretius Humour' or 'Schadenfreude', it has traditionally been explained by the superiority theory, which sees it as the expression of a feeling of superiority over the victim of the misfortune. Such an evaluation seems to be associated with a high level of understanding, however, and it is unlikely that this is what is happening in people with profound handicap.

Taking into account other precursors to laughing in the subjects, such as sneezing, I proposed earlier that the laughter may be generated by the strangeness of the voice tone. This may be explained by the incongruity theory, in that an expectation of how someone's voice will normally sound is upset. This is a more promising explanation, but it involves the evaluation and interpretation of the event, and there is the possibility that this may also be beyond the capabilities of the subjects.



Perhaps the explanation is simpler and more direct than that, and the subjects merely laugh at something which is different (novelty). But such a physical explanation seems too simple, as an important component seems to be that a known carer performs the unusual and unexpected act - the laugh is often dependant on a member of family or known staff being the one involved, and many subjects laugh more when it is a particular person (such as a brother). This implies that some evaluation is going on. It is interesting that detection of these responses is focussed on features of the human voice or body movements, which parallels the sensitivity of the infants to these same features of the mother.

The involvement of a significant cognitive component in the major theories of laughter therefore limits their usefulness in explaining the behaviour of people with profound handicap. It may therefore be more productive to look at theories of the development of humour in infants. Unfortunately, such research is comparatively rare, most studies looking at the development of verbal humour in subjects older than infants. A few researchers have studied humour in infants and very young children, however, and have looked for the earliest signs of a humorous response. Here again, however, the emphasis has been very firmly on the cognitive aspects of this development. Humour is seen as a change in arousal, produced by the perception of some change in the environment. The age at which laughter first appears is therefore taken to be the age at which the cognitive capacities which allow the detection of this change first appear.

McGhee (1983) is amongst those who have taken a Piagetian approach to the development of humour and believes that the cognitive abilities necessary for laughter are the symbolic capacities which develop in the second year. According to this theory, laughter is caused by the perception of an incongruity in the environment, which a child is not able to do until the development of the new ways of perceiving and thinking about objects which take place in the last sub-stage (internalization of schemes) of the Piagetian sensorimotor stage. Thus, laughter cannot occur before 18 months.

But laughter appears long before 18 months, and fantasy play and symbolic thought does not appear to be necessary. Watson (1972) and Papousek (1969) have separately found that infants only 3 to 4 months old will respond with smiling and laughter when a receptive system (a mobile and display of lights, respectively) is arranged so that changes in the system are contingent upon the infant's movements.

Thus, an infant moves an arm, the mobile moves and the infant laughs. This is seen as laughing at a 'contingency', and is related to the 'pleasure at mastery' demonstrated by an infant when correctly solving a problem, first described by Piaget (1962).

Similarly, Pien and Rothbart (1983) also believe that the cognitive processes responsible for humour develop early in the first year, though they see this as detection of incongruity rather than contingency. They argue that an infant can recognize an incongruous event (that an incoming stimulus does not match a previously established internal standard) as early as 4 months, and that this raises the level of arousal in a sharp, rewarding 'jag'. They also believe that this can only produce a humorous response if the infant is in a playful mood. Evidence for this theory comes from a study by Sroufe and Waters (1976) which looked at laughing in infants aged 7, 10 and 12 months in response to actions of the mother. They found that the earliest age at which an infant laughed at an incongruous situation (as opposed to tactile stimulation), was 8 months, when the mother put a dishcloth in her mouth. At ages over 12 months, they found that infants will laugh at their mothers walking 'like a penguin'.

Have these explanations any relevance for the the humour response in people with profound handicap? The study by Sroufe and Waters has some similarities with individual examples of subjects laughing at a carers behaviour, though my research suggests that the tone of voice (prosody) used by the mothers in this experiment may have played a significant part in the infants reaction. Infants under six months of age typically laugh and squeal with delight in performances of nursery rhymes and songs, synchronizing their vocalizations with the mother's behaviour at the climax of the performance, and this is clearly related to prosody.

Generally, however, the explanations offered for the development of humour in infants is unsatisfactory. In these explanations, the affective component is clearly secondary to the cognitive, and humour is seen as a change in arousal which can be completely explained by a cognitive process. This ignores the social role of humour, which is surely the most important. It is notable that the subjects responded only to interpersonal events and never laughed at contingencies or incongruities involving only objects. Pien and Rothbart (1983) at least recognize the importance of the mood of the infant: if he is not in a playful mood, he will not laugh. A mother or partner actually provides all of the qualities necessary for inducing laughter in an infant identified by these theories: a range of contingencies and incongruities and a playful

atmosphere. In fact, when an infant does laugh at a contingency involving objects, such as that described in Watson's experiment (1972), it is possible that the infant laughs because he believes that another human being is behind the contingency. At any rate, unless another human does intervene the infant appears to bore with a simple contingency very quickly.

It does appear, then, that very young infants can detect a contingency or an incongruity and, in the right circumstances, find them funny. A theory which does not stress the interpersonal aspects is not useful, however. One approach to humour which does do this are theories based upon evolution and social function. This was first proposed by Darwin (1872), who believed that laughter is a social signal used to express comfort in play and thus to facilitate cooperation. This view has received support from the many studies which have observed similar facial expressions across many different cultures, and expressions in primates which closely resemble those of man, suggesting an innate basis for expression and a pattern of evolution (Ekman, 1973). In particular, valuable evidence has come from a recent study of humour in primates: Van Hoof (1989) has argued that a 'play face' (relaxed with an open mouth) is used as an introduction to a playful interaction, signalling to others that a behaviour is not aggressive and that there is a willingness to play. Breathing during this display is fast and shallow, and bears an uncanny resemblance to laughing. This comparison between the function of humour in man and other species is further reinforced by a study by Sroufe and Wunsch (1972), which looked at the variables that are effective in stimulating laughter in 4- to 12-month-olds, such as tactile (e.g. bouncing on knee), acoustic (e.g. making a 'boom' noise), and visual (e.g. 'peek-a-boo game'). They found that those variables which were successful in stimulating laughter in infants were very similar to those observed with primates, the important factor in all of them being the spontaneity and the unpredictability of the agent. Humour, then, can be seen as the playful interpretation of an unexpected configuration of events, with its roots in a social signal intended to convey a willingness to play.

This makes a great deal of sense, and offers a way of understanding the interpersonal basis of humour in infants and in people with profound handicap. The presence of vaguely similar capacities in primates also suggests that these are located at a low level in the brain, though the importance of voice tone and prosody to people with profound handicap is not seen in primates.

Are these observations confirmed in research into the humour of people with a mental handicap? Unfortunately, here also the research concerns higher ability levels than those of people with profound handicap (e.g. Zigler, 1966). Cicchetti and Sroufe (1976) have looked at the development of the humorous response in Down's Syndrome infants, and found that it correlates very closely with intellectual development. Similarly, a study by Fewell (1985) attempted to replicate Cicchetti and Sroufe by looking at the smiling and laughing reactions of 4, 10 and 16 month old Down's Syndrome infants to the incongruity stimuli used in the Sroufe and Waters (1976) study. He found a delayed but similar increase with age. Thus these studies have also concentrated on cognitive aspects of humour. There are no studies looking at the interpersonal basis of humour, and none have used subjects with profound handicap.

Therefore, in attempting to understand the humour response in people with profound handicap, the main source of evidence is research on the development of humour in infants, though these studies have looked at cognitive rather than interpersonal aspects, and researchers have not been able to reach a consensus about the abilities involved or the age at which they first appear. In fact, the presence of a humour response in people with profound handicap would seem to have great relevance for the study of humour in infants: if an individual with profound handicap and a very low mental age can laugh at incongruity, then symbolic thought may not be a necessary precursor. Precursors may actually be even harder to identify if we take into account the mental ages of all of people with profound handicap that show this ability. If it is the same ability that was investigated by Sroufe and Waters (1976), then many of these individuals may be operating below even the 8 month age level established as necessary in their study. That people with profound handicap may have this ability in spite of the handicaps and brain damage associated with the condition is remarkable.

Despite these problems, it is useful to compare the responses of people with profound handicap with those of infants. Laughter can then be seen in terms of the perception of an unusual and unexpected change in the behaviour of a familiar other, and a reaction to it. This is dependant on the mood of the subject, and also the identity of the other person involved: usually, the subjects responded far more to very well known carers. In all examples of laughing in the subjects, there is an emphasis on the voice tone and body movements of other people. These convey rich information about a person's motivation (and contingency), and the awareness that the subjects show of



these seems to reflect a predisposition to engage with human actions. In people with profound handicap, humour is clearly a social act, rooted in the interpersonal situation, and triggered by the careful observation of changes in another persons behaviour, for which the perceptual system appears to be tuned.

However we may characterize the laughter response, it remains very important to the carers who see it, I think, as a reminder that people with profound handicap are, after all, people seeking communication. They are undoubtedly right: to find such a widespread, complex, discriminating and wholly human ability in people with profound handicap is certainly encouraging.

*Other emotional responses compared to those of infants:* The humorous responses of people with profound handicap are an important part of their emotional system, but people with profound handicap also display a wide variety of other emotional responses to people and events: some may use a frightened expression if they are about to fall, for example; others may cry if hit by another child; and almost all will smile at a familiar carer or during play. Evidence from the carers suggests that these can be appropriate reactions to the context, and that facial expressions used by people with profound handicap are easily recognizable.

Here again, we are faced with the problem of reconciling these characteristics with the undeniably limited cognitive functioning of people with profound handicap. In fact, in some cases subjects displayed very few abilities or intentional behaviours apart from those that were emotional responses.

In attempting to understand the emotional development of people with profound handicap, the findings from studies of normal development are an excellent starting point: A newborn infant is attracted to the human face and has the capacity to produce all facial expressions. Eye contact is established by 6 weeks. Also at six weeks, there is pleasure at recognition of the mother, interest in objects, and unease in the presence of a stranger. At two months, the infant responds appropriately to the emotions expressed by the mother: the face of others is scanned and the expressions of feeling instantly perceived. At four months the play between mother and infant becomes more vigorous. Gradually, the infant becomes more interested in the environment and less in the mother, until he becomes interested in both through cooperative actions. Self-awareness and self-regard in mirrors increases over the first year and after six months becomes associated with 'showing-off' and humorous performances.

There is a thread running through this development: the infant comprehends the emotions of others, and uses emotional expression to regulate affectional interaction. This occurs in the first 2 months, before the infant masters the prehension of objects. Basically, persons are perceived and acted upon in a fundamentally different way from objects.

How much of this can we see in the behaviour of people with profound handicap? The principles of this development in normal infants appears to explain many aspects of behaviour seen in this research with people with profound handicap. Self awareness and cooperative acts with other individuals do not develop naturally in people with profound handicap, but the emotional system on which such developments are built is present. Subjects demonstrated the capacity to express emotions which can be correctly interpreted by a partner seeking communication. Interest in objects, in contrast, is sporadic, and knowledge of object use and causal relationships exceedingly sparse, yet all subjects demonstrated recognition of people. Some subjects also seemed able to correctly interpret the emotional expressions of others, acting appropriately in response, but the limits of this ability are not known.

Interestingly, the sessions showed that most of the subjects do attempt to regulate interaction with their emotional expressions. Some smile and laugh to encourage interaction, others produce angry expressions and strike out to avoid it. Some produce sad expressions in an effort to get attention. All subjects will look away to terminate engagement. It is reasonable to conclude that these expressions are controlled by an organized motivational system and that the consequences - the initiation, continuation or termination of an engagement - are those desired by the subject.

These expressive behaviours in people with profound handicap appear to have a close similarity in form and intention with the use of emotional expression in infants. There are differences, of course: people with profound handicap have a reduced attention span and have problems maintaining some basic social behaviours such as eye contact. Nevertheless, the similarities of expression and engagement are strong enough to suggest that the findings concerning infant development may be used to increase our understanding of the behaviour of people with profound handicap.

It is also possible that the reverse may be true. A problem in understanding the behaviour of people with profound handicap concerns explanations of how some



aspects of intelligence and motivation are more advanced and better preserved than others. This is essentially the same problem faced by theories of development: in infancy effective emotional and communicative behaviours, and the understanding of the existence of other human beings, seem to appear well in advance of the development of the mental representation of objects, as this was outlined by Piaget (see Chapter 4). Similarly, many people with profound handicap are able to communicate and form relationships with carers in the absence of any higher order cognitive functioning. Some show hardly any signs of cognitive functioning at all, but have a full range of active emotions. The implication is that the emotional system may develop and act separately from higher order cognitive functioning.

The relationship of emotion to cognition is a controversial and under researched area of psychology. The nature of the interaction between affect and thought is difficult to establish, but Zajonc (1984) has argued that affect develops first and can function independently, and cites some experimental evidence to support this. Zajonc's theory is an attractive one, and his claim that 'preferences need no inferences' makes a lot of sense, especially in the light of the many preferences regularly demonstrated by people with profound handicap: I do not believe any of the subjects could know why they liked traveling on the minibus, or why they felt happy when they heard a particular piece of music. I do not believe I could say why such things give me pleasure, either!

Although Zajonc may be wrong, it is hard to think of any explanation for the advanced development of emotions in infants and in people with profound handicap which can be reconciled with traditional cognitive developmental theory. In infants, the full spectrum of emotions are present at birth and an infant will regulate its own emotions in relation to the emotional expression of the mother at the age of only two months. These abilities are far in advance of the intellectual abilities of infants of the same age. Piagetian theory has been unable to recognize or explain this. Piaget seldom mentioned emotions, and believed that they conformed to the same principles that govern the building up of the representations of operations performed on objects. This is patently not the case. Clearly, people with profound handicap do not need to understand the object concept in order to communicate or recognize a carer. Interpersonal awareness is not dependant upon knowledge of passive things, or on the attainment of a particular stage of cognitive development.

Gradually, the importance of the emotions in development is being recognized. The presence of an active emotional system in people with profound handicap, who do not demonstrate high level mental functioning, lends support to theories of the primacy of affect, but what relevance has it for people with profound handicap themselves, and for their care?

The answer to this question must be that it is highly significant. The presence of emotions is perhaps one of the few things that we can agree on that make us human and has undeniable importance in the formation of human relationships:

"They serve as the first means of communication between the mother and her infant; she smiles approval, and thus encourages her child on the right path, or frowns disapproval. We readily perceive sympathy in others by their expressions; our sufferings are thus mitigated and our pleasures increased; and our mutual good feeling is thus strengthened.....Expression is certainly of importance for the welfare of mankind." (Charles Darwin, 1872, p.365)

Moreover, the importance of the emotions in mental functioning should also be recognized. Trevarthen (1984) believes that it is possible that the emotional system serves a regulatory function in directing the growth of intellectual abilities and this is an attractive theory with great relevance for the care and teaching of people with profound handicap. Whether this is true or not, the presence of emotions in people with profound handicap is an interesting aspect of their behaviour that has been overlooked. Its importance has been recognized by parents and carers for some time. It should now be recognized by professional psychologists and by their research.

#### *2.4 Learning in people with profound handicap*

This research has shown that many people with profound handicap can demonstrate isolated examples of spontaneous learning: learning which is not the result of training. Earlier, I presented the evidence for this, and described how this learning differs from behaviour trained in behaviour modification programmes. Here, I would like to look a little closer at this phenomenon.

Although rarely mentioned in the research literature, some professionals working with people with profound handicap have long known that in certain situations some learning can occur. What relevance has this learning for training? The first answer which comes to mind is 'not much', because its effects are isolated and

unpredictable. Although it is true that this learning cannot be controlled and is therefore of little direct use to carers, it does provide some insight into the cognitive processes of people with profound handicap. It shows that many people with profound handicap can learn some quite complicated behaviour patterns without artificially controlled reinforcement schedules.

The big question here is why do they learn at all? What are the characteristics of this learning that differentiate it from behaviour modification training? The end result is certainly different. Spontaneous learning seems to survive long periods without reinforcement (e.g. play routines learnt with a carer were remembered when the carer returned after a long absence), whereas Ellis et al (1986) found that forgetting occurred in their subjects after one day. Spontaneous learning also occasionally shows some indications of spontaneous generalization, with some actions (e.g. raising a foot to be tickled) being used with different carers and in different locations.

What makes this learning more effective? As mentioned above, reinforcement is probably less consistent in spontaneous learning. One way to answer this question is to consider the part played by motivation. Spontaneous learning invariably involves immediate satiation of an important need, such as hunger or play (interestingly, play does feature very often as the motivation for spontaneous learning). This may not seem surprising, but in behaviour modification similar rewards (especially food) are often used as reinforcement, and the results appear to be very different.

Perhaps an important advantage in spontaneous learning is that there is a direct relationship between the behaviour and the reward. The motivation, the idea, and the behaviour are the product of one individual, and the reward follows immediately. In an artificially imposed schedule of reinforcement, the reward is produced by another person, who awards it when satisfied that a behaviour has reached a criterion. It may be possible that the subject finds it more difficult to relate a behaviour to a reward when the reward is not a direct consequence of that behaviour, but follows shortly after and is produced by the intervention of another person and methodological complications may cause reinforcement to be delayed on several trials. People with profound handicap may also have difficulties in associating the reward with a particular behaviour, and not know what behaviours are being reinforced (which would not happen in spontaneous learning).

The reinforcement value of the reward may also be far higher in spontaneous learning. If a subject shows spontaneous learning in order to achieve a tickle on the foot from the carer, for example, this is clearly highly rewarding for him, and possibly much more so than whatever has been chosen by a psychologist to use as reinforcement<sup>1</sup>.

I do not know if any of these tentative explanations are really satisfactory, but isolated forms of spontaneous learning remain an intriguing ability retained by a great many people with profound handicap. In some cases such feats of spontaneous learning should be way beyond the capacities of the individual, as estimated by assessments of ability or performance on traditional training programmes. This is a paradox which is certainly worthy of further study.

### **3. The Care of people with profound handicap**

#### *3.1 Improving Assessments*

Assessments play an important part in the provision of care for people with profound handicap, being used to allocate services and monitor progress. There are a variety of assessments in use with people with profound handicap. These tend to be psychometric, developmental, or Piagetian in sentiment. Behaviour scales or occasionally assessments of an aspect of behaviour (e.g. communication) are also used. There are problems with all these procedures, however, which may make the use of assessments in the provision of appropriate care less effective. The majority were not designed for use with people with profound handicap but for normal infants or the less mentally handicapped, and may therefore contain inappropriate components. Assessments which rely on testing the subject may find that testing is impossible because of behaviour problems, or that the scores obtained on different occasions are wildly divergent. Such assessments may also be limited in the behaviours which they consider. Assessments which rely on carers reports of the behaviour of the subject also face problems: they may, for example, overlook a behaviour which is present in the subject but not observed by the carer.

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<sup>1</sup>Observing such spontaneous learning may actually provide a list of successful reinforcers.

It is hard to imagine any assessment which solves all of these problems. One interesting development has been the suggestion made by Goode and Gaddy (1976) that careful, long-term naturalistic observation of people with profound handicap be used to determine preferences. Building upon this idea, I believe that a valuable contribution would be to use a regular video analysis similar to the one used in this thesis. Each individual would be filmed with a familiar carer so that the range of behaviours can be observed in detail. In this study only two sessions were used, but it is conceivable that for each subject it would be possible to film half-hour sessions each month. The sessions would be semi-structured: The carer would be encouraged to follow the lead of the person with profound handicap in the way the play session develops, but would be given information on techniques for communicating with people with profound handicap, and a list of those techniques which have worked with this particular person. Part of the session would involve a 'testing' of these techniques to determine preferences in the subject. Analysis of the behaviour would be similar to that devised in this research, but could be made considerably simpler. It should be carried out as soon as possible after the recording and retained in a standard form for future reference.

The result of such an assessment procedure, implemented each month, would be to build up a large amount of reliable information on each subject's behavioural characteristics, including: communicative ability, emotional reactions, and instances of spontaneous learning. It would also allow for the identification of patterns of care which are successful in obtaining engagement with a given subject, and changes in behaviour and preferences over time could be noted and plotted.

Of course, this assessment would supplement and not replace more traditional assessments of ability, but this 'ecological' procedure does have a number of advantages. The behaviour is observed in a natural environment and the context is a play situation rather than a test situation. These conditions will allow a much greater chance of obtaining engagement during the session and reliable, consistent information will be obtained over time. This procedure also takes into account all of the subject's behaviours and is therefore far more representative of what a subject is actually like - and what special requirements of care he may have - than is a score obtained on a formal test. The assessment is designed specifically for people with profound handicap, can be shaped for each individual, and has immediate practical relevance for care.



Such a procedure may be considered impractical and time consuming, but the equipment to enable videotaping and play-back of sessions are now widely available in hospitals and schools, and the advantages of video records are shown by the following observations: I found that on occasions, while watching tapes of sessions, I was able to identify preferences of the subject which the carer had failed to pick up. For example, one subject consistently terminated an engagement when the carer introduced a toy, and always rejoined when the carer tried physical contact, even initiating this twice. During the session this all happened so quickly, or was so subtle, that neither I nor the carer noticed it, but it became clear on viewing the videotape. In another case, an unresponsive blind subject who did not seem to show any awareness of other people seemed to do nothing during a session. When analysing the tape later, however, I noticed that her stereotyped head movements ceased every time the carer rattled a toy against her hands, and started again when the carer stopped. On closer inspection, I was able to observe that the subject also moved her head to one side, orienting to the carer. Feedback from carers confirms that video analysis is a valuable means of assessing preference and ability in the subject, and moreover of providing information on the success of the carer's performance.

Finally, there is one other approach to assessment for which the results of this research have some relevance: the use of the humorous response as an indicator of level of development, as proposed by Fewell (1986). Fewell has argued that a test for the presence of humour in a subject is actually much more reliable than any other test of mental age. The methods that he used were those devised by previous studies of the development of humour in normal infants (Sroufe and Waters, 1976) and Down's Syndrome infants (Cicchetti and Sroufe, 1976), whereby a mother is instructed to perform a series of humorous behaviours and the reactions of the child are observed to determine the age of mental functioning. This procedure was applied to the assessment of young mildly and severely mentally handicapped children. Although Fewell did not look at children with profound handicap, this is an intriguing idea. The presence of such a response in people with profound handicap (as shown in this thesis) actually makes correct identification of the ages at which these humorous reactions first occur harder to establish, but the presence of this ability does appear to divide the population into able and less able groups.

Clearly, the problems in assessment will take time to overcome. Assessment in any area of psychology is controversial and difficult, but with people with profound handicap these problems multiply. I believe a promising development is in the use of



video. One way forward is to recognize the importance of all aspects of behaviour, and to place these in relation to each other, and on a developmental framework. This thesis is a modest attempt to begin this process.

### *3.2 Subtypes of Profound Mental Handicap*

Few investigators have looked at the possibility of subdividing the population of people with profound handicap. Amongst those who have made the attempt are Ellis and his colleagues (1982), who propose that people with profound handicap be divided into high and low ability groups. They found significant differences between these groups in a study of learning capacity, with two of the 14 in the low ability group being unable to learn anything at all after 36 days, and nine others producing results equal to chance. In addition, the two groups scored significantly differently on I.Q. scores and the low ability group displayed more maladaptive and inappropriate behaviours.

Ware and Evans (1986), in a study of interaction in a special education classroom, also divided their population of 9 children with profound handicap into high and low ability groups. In this case, however, the distinction was based upon responsiveness to attempts at interaction from the teacher. The high group was significantly more likely to respond positively to an approach by a teacher, had a higher rate of behaviour, and overall made over twice the number of responses during the observations as the low group. The distinction between the two groups was also correlated with the subjects' scores on the Bayley scales, the high group achieving significantly higher developmental scores. The low group was also perceived by teachers to be less attractive, less intelligent and less responsive.

The findings of these studies are similar to that of a comprehensive study by Hotte et al (Hotte, Monroe and Philbrook, 1984). They divided 207 institutionalized residents into high and low profound groups according to scores on the Vineland Social Maturity Scale. The high group had I.Q.'s which were approximately between 10 and 19, and the low group below 9. After three years, they compared the groups again and found significant differences between them in the gains that had been produced by training. The low group made a mean gain of one month in development on the Vineland Scale, the high group a gain of eleven months. There were many individual differences, however: 77% of the high group and 54% of the low group

made improvements, 4% of the high and 17% of the low groups remained the same, and 19% of the high and 29% of the low groups actually achieved lower scores. At the re-test, several high group subjects were considered better classified as having a severe mental handicap.

Hotte et al suggest that the classification of profound mental handicap is too broad and that differentiating between high and low groups may be an important step when considering programming priorities, needs, and cost effectiveness. They claim that their results clearly show that the high profound group benefits much more from training

There may be problems with these conclusions, however. The low profound group may be more physically handicapped, which is not only a barrier to performance, but also makes them less attractive and less likely to receive attention from staff (see Chapter 3). The importance of attracting attention from the carers and therefore receiving better training should not be underestimated. In fact, Hotte et al's paper mentions that the high profound group received an average of 2.5 hours training a week more than the low profound group, though they do not say why. Over three years, this is a highly significant difference in exposure to training.

A different approach to subgrouping people with profound handicap has been taken by Rago (1977). Using ethological techniques, he studied territoriality and dominance hierarchies amongst a group of institutionalized subjects. After careful observation, he found that it was possible to divide them into dominant and subordinate groups by their consistent patterns of gaze aversion and touching behaviours. After a hierarchy had been obtained, he matched subjects together and placed them on separate wards. The number of aggressive incidents dropped dramatically, and remained stable in a follow up. Thus it was possible to identify a stable behaviour in people with profound handicap which differentiated two groups who appeared to be functioning on different levels.

The results of this thesis have some bearing on these attempts to sub-divided people with profound handicap. The analysis of the data in Chapter 6 consistently reveals that the 66 subjects can be divided into an able, responsive group, and a smaller unresponsive group. The distinction seems to confirm a general division according to ability, and correlates with several behavioural variables, especially responsiveness and expressiveness. The less able group were more likely to be

resident in hospital, and have additional physical or sensory handicaps. It is easy to see how the groups obtained in this division may correspond closely with the groups obtained in the previous studies, and the division into able and less able seems particularly robust.

It must be remembered, however, that the extremely wide individual differences people with profound handicap makes any rigid distinction between sub-groups difficult. Such a distinction must also take into account the potential for change in each individual, and the effects that medication, residence and additional handicap may have on this potential. Until more research in these areas is completed, the limits of the potential for change in even the least able individual cannot be ascertained with confidence.

In general, then, the distinction between high and low performing groups seems a valid one, but it needs to be qualified to take into account potential for change, and the influence of attention from carers, physical handicap or medication. There also needs to be an assessment procedure which will reliably make this distinction. As noted earlier, the problems in devising any reliable assessment for use with profound mental handicap, and an adequate definition of profound mental handicap itself, suggest that this is unlikely to be available in the near future.

### *3.3 Intervention*

The most important topic for future research with respect to improving care will be to develop more effective intervention procedures. At the moment, intervention comes in two forms: intervention in the behaviour of the carer or of people with profound handicap.

Intervention into the techniques used by carers in order to improve their effectiveness appears to be much easier than the second form of intervention, but at present is much rarer. Several studies have tried to train staff in particular methods of care or attempted a re-organization of roles, and these have been generally successful (see Chapter 3). Amongst the more successful are those that have concentrated on improving interaction. An important area is the extension of this work to parents. The 'Moving in Sympathy' project is one example of this approach. This project has been concerned exclusively with the identification of effective techniques for

communicating with people with profound handicap, and has applied these findings to the training of parents, carers and teachers.

Intervention in the behaviour of people with profound handicap has traditionally involved behaviour modification. As I have shown, the aims of such intervention programmes tend to be the same: to train self help skills and reduce maladaptive behaviours, and occasionally to introduce social behaviours. These programmes have had mixed results.

The findings of this thesis have some relevance for intervention. It may be possible to conduct a similar programme to the 'Moving in Sympathy' project - one which concentrates on communicative and emotional behaviours - but which focuses on the behaviour of people with profound handicap rather than their carers. This project would identify abilities in different individuals and determine ways of introducing them to others. In this way adaptive behaviours which occur naturally in some of people with profound handicap could be introduced to those who have so far not developed them.

A theoretical question which remains, however, is the degree to which change in the behaviour of people with profound handicap is possible. Here, this thesis is encouraging. Evidence of recent, positive changes in behaviour was seen in several subjects, including one whose behaviour has become much more social over the last two years as a result of participation in a group taking part in a programme of 'music and movement' (moving in time with music during one-to-one interaction with a carer). This subject is in his mid-forties, indicating that potential for change may remain untapped in a great many people with profound handicap over many years.

In fact, there is some evidence that much depends upon the approach taken in intervention. Although there are exceptions, such as the case just described, intervention still usually involves a behaviour modification programme. A slightly different approach has been taken by Samaras and Ball (1975). In an extremely intriguing study, they noticed the complete absence of any naturally occurring cooperative behaviour in people with profound handicap (behaviour in which two or more individuals work together in order to accomplish a task), and attempted to introduce it. They did this by using a machine which offered food, but could only be operated by two individuals. After a while, and after some training using faded cuing, several subjects managed to operate it when paired with each other. Some experienced

subjects paired with a partner who was new to the apparatus even seemed to take the initiative and encourage them to operate it. There also appeared to be an increase in social behaviour, but this was not generalized outside of the experimental setting.

This finding appears to be quite remarkable. Cooperative behaviour is of the utmost importance in human development and the development of cooperative awareness towards the end of the first year is a major developmental milestone. If this procedure did succeed in teaching cooperation (and the lack of generalization does throw some doubt on this), it is worth asking why. Perhaps one reason lies in the approach taken by Samaras and Ball. The 'cooperative machine' did not involve any staff. It was developed for use with schizophrenics, and in many ways its application here parallels the willingness to adopt ethological techniques seen in Cleland's research. This machine automatically gives food as a reward when buttons are pressed. The subjects are therefore motivated, and appear to be demonstrating something remarkably similar to the complex behaviour which occasionally occurs in spontaneous learning.

Cooperative behaviour is not seen naturally in people with profound handicap: there is only one documented account of anything approaching it (Cleland, 1979a). It is possible that in the Samaras and Ball experiment subjects were merely learning specific responses rather than a general principle, but if cooperativeness is what is being learnt then it offers the possibility that many aspects of behaviour could prove amenable to such intervention. As yet, this is the only study of its kind.

We cannot be certain, yet, that it is possible to introduce such fundamental changes in behaviour, though this remains a tantalizing possibility. There are, however, many separate but important behaviours identified in this research which may lend themselves to intervention. Eye contact, facial expressions, touching, and many other communicative behaviours can be regularly reinforced in a social context, as can attempts by people with profound handicap to initiate an interaction.. The result would be an increase in the frequency and richness of the interactions with carers and a major improvement in the quality of life of people with profound handicap.

The best way to achieve such a change is to recognize the importance of communicative and emotional behaviours to care. Too often carers simply do not have time to attend to all of the needs of people with profound handicap and such



behaviours are ignored because of an over-emphasis on teaching or training, or on the physical aspects of care. Perhaps it is time that we recognized this.

#### **4. Future Research**

This thesis has raised several issues which need further research before any firm conclusions can be reached. People with profound handicap are a fascinating and rewarding group to study and there is a very great deal that we have yet to find out about them. Reading again the research in this thesis, I don't think that I have begun to explore many aspects of the behaviour of people with profound handicap that desperately need to be explored, but I believe that I have made a start.

There is a great need to break out of the clichés of investigation in this area. The group under study needs to be carefully defined, the less able individuals have to be attended to, and the research has to look at all aspects of behaviour. In this study I have deliberately steered away from conducting research based on assessments of mental ability and have concentrated on social aspects. I believe that the emotional and communicative abilities of people with profound handicap have proved worthy of study. One of the next steps is to define precisely the relationship of these abilities with other cognitive abilities. I have discussed some ideas concerning the relationship in this thesis, but the next step in investigating this would have to be a longitudinal study which takes both approaches and compares the two sets of results.

The best way to do this would be to take a sample of people with profound handicap and film them interacting with their carer in the same environment (a comfortable studio), and before or after this session administer a selection of the available cognitive assessments. This may be time consuming and expensive. Subjects living at home should be included, but they would ideally need to be brought to the studio for filming with a parent. This would have to be repeated over several months. Eventually, it may be possible to plot the development of cognitive and communicative abilities, and to link the appearance of communicative behaviours with assessment scores, or even to prove that communicative behaviours are consistently more advanced than assessment scores would suggest. An important consideration needs to be the duration of the study: long term studies of people with profound handicap are few and far between, and tend to concentrate on gross, often temporary, changes in cognitive assessment scores.



Another interesting experiment suggested by the research in this thesis would be to study the humour response in people with profound handicap using the stimuli used in the Sroufe and Waters (1976) experiment. I would have liked time to carry this out, but perhaps the results can already be guessed from the anecdotal evidence we have available and, since people with profound handicap are so unpredictable, it is quite possible that such an experiment would have to be extremely long.

One tentative conclusion of this research is that medication, especially phenobarbitone and anti-epileptic medication, may depress the behaviour of people with profound handicap. It is important that this possibility be recognized. There is often an unspoken view that factors such as these do not matter when the subjects have a profound handicap, because 'they are so handicapped anyway'. This is not justified, and studies should always list the medication of the subjects. Sadly, I do not know of any that has done so. There is still much that we need to know about the effect of medication on people with profound handicap. In particular, it is feasible that those subjects receiving drugs were already less able as a group before the medication was prescribed. A carefully controlled study which observes the effects of changes in medication is needed. This should use a measure of social responsiveness as well as the more traditional assessments of ability.

Similar conclusions can be drawn from the finding that the visually handicapped are less responsive. It is important to appreciate that although an individual may already have devastating cognitive handicaps, the additional presence of blindness adds an experience of extreme isolation and will make an important difference to development and the effects of care. There should therefore be attempts to find ways of compensating for it.

There are a number of other issues raised in this research that deserve to be mentioned and I could list many areas in which I believe it would be worthwhile to conduct future research. I will restrict the rest of this section to the more interesting of them, however. The disruption of sleeping is one such area. The fact that some individuals will wake early and begin their daily cycle (even at 3 A.M.), whilst others can be put to bed early by speeding up their routine (which 'fools' them into thinking it is 'bedtime'), suggests that there is no external 'fine-tuning' of the internal 'body-clock' and that this can be manipulated. It is well documented (e.g. Cleland, 1979a) that a number of people with profound handicap have reversed their daily cycle, and will spend their days asleep and their nights awake. This may be related to problems in

the 'body-clock', but I do not think so: these people may have felt that activity at night has certain advantages, including less chance of carers restricting activity. It may therefore represent a form of spontaneous learning. If I am right, then a plan by Leath and Cleland (1974) to alter staffing shifts to cover people with profound handicap who are awake at night may result in them going back to sleep again!

A way to increase our understanding of the 'body-clock' would be to keep a careful record of the sleep-wake cycles of a number of people with profound handicap (this should not be restricted to those in institutions). It may also be possible to measure the brain wave activity of people with profound handicap whilst they are sleeping and it would certainly be interesting to look at stages of sleeping and dreaming in people with profound handicap. Eventually it may be possible to link those individuals with persistent disruption to the sleep-wake cycle with specific patterns of brain damage.

The sounds made by people with profound handicap are quite varied. It seems that they are also more likely to be used during engagement with a carer. It would be useful to obtain spectrograph recordings of these and to compare them with the vocalizations of infants of different ages (and possibly of the higher primates). It may also be possible to look at the function of these sounds in their contexts. This research points to the possibility of turn-taking behaviours in people with profound handicap. Perhaps another analysis could go further, and separate the repetitive and stereotypic from the meaningful sounds made by different individuals.

On this subject, the lack of any language in people with profound handicap is a fascinating and particularly important issue. The reason for it is completely obscure. There is certainly the opportunity to acquire a language - the environment is as full of words being used by adults as it is for other infants who do develop language. Although some individuals may have a problem in actually speaking, there is usually the opportunity to sign with hands and face. When physical problems limit these movements too, there is always the opportunity to signal receptive understanding with gross body movements. None of people with profound handicap demonstrate a level of receptive understanding which is anywhere near high enough for us to conclude that they have a language. The failure of development must therefore be due to a problem in either motivation or learning capacity.

In the past, studies have seen the cause as one of motivation, and have imposed a motivation from outside by using behaviour modification techniques. These have met with limited success. The conclusion we can reach is either that the techniques have not yet been sufficiently refined, and that when they are people with profound handicap will learn signing or speech, or that the brain has suffered such damage that the capacity to learn language is really absent, despite the retention of a capacity for an earlier level of communication.

Alternatively, we might examine the ability of people with profound handicap to engage in this early communication, look for its limitations, and attempt to promote it to its widest extent. Perhaps then we shall find out whether the next step - the jump to true language - is really beyond the capacities of people with profound handicap.

## **5. Concluding Remarks**

This research has clearly demonstrated the usefulness of a framework for research with people with profound handicap which takes into account all aspects of human development. Without this, many of the results would not have been found.

What has been found? All of the subjects in this study responded in some degree to their carer. The majority of the subjects produced a wide variety of communicative and emotional behaviours. They are responsive and reactive to their environment, and they respond to other people as if they were people. In short, people with profound handicap display characteristics of behaviour which place them firmly in a uniquely human world.

This thesis has attempted to provide an outline of what people with a profound handicap are actually like. Hopefully, I have also begun to investigate why they are like this. I have used comparable studies of infant behaviour to illuminate the development of behaviours in the people with profound handicap and have suggested that many of these behaviours could have a subcortical basis.

This thesis has also contained a critique of the research which has been conducted into people with profound handicap so far. There is not a great deal. Much of it has been based upon behaviour modification and I have been critical of this approach. I have also stressed the importance of a framework for understanding

behaviour and bringing together findings from different areas of research.

Where does research go from here? I began my criticism of behaviour modification by recognizing its achievements. I would like to state again that the potential benefit of behaviour modification is enormous. The main problem, however, is that the special problems of working with people with profound handicap are not usually acknowledged. In particular, there is a tendency to assume that training is merely a matter of selecting a target behaviour and working out a reinforcement schedule. The implication is that everything can be trained given enough time. In principle, the logical conclusion of this is that given enough time an individual with profound handicap can be taught anything - to drive a motor car, for example.

The fact is that although people with profound handicap can learn there will be limits to this ability. These limits can only be identified when we have a clear understanding of the condition. One limitation seems to be in the ability to acquire language skills, where people with profound handicap have a particular deficit, but without further research it is impossible to know how successful intervention can be. It is therefore essential to have an understanding of the nature of profound mental handicap in order to plan appropriate goals.

Many researchers do recognize this to some extent. They use the appearance of behaviours in normal development to plan the order in which behaviours are to be trained to people with profound handicap. These behaviours are broken down into component parts. Here again, however, it is important to recognize the differences in the development of behaviours between people with profound handicap and infants, in order ultimately to determine the most suitable method of de-constructing behaviours, the most effective reinforcers, and the possibilities for successful training.

Above all, the dynamics of learning are different in people with profound handicap, and this has to be appreciated. If this approach is taken, training may become more effective and more relevant to the lives of people with profound handicap. Given all of this, there is no need to have a pessimistic view of the potential of people with profound handicap in the future.

It is important, then, to study the behaviour of people with profound handicap and not take it for granted. It is also important that all aspects are studied, including the emotional and the social, which at first may not appear to have much practical use. This is the main point of this thesis.

The history of the scientific study of people with profound handicap is littered with studies reporting a bleak list of abilities which they do not possess. Some have tried to change that picture by selecting as subjects the more able people with profound handicap. My research has hopefully demonstrated that this is unnecessary: a range of important abilities can be identified in all people with profound handicap if the appropriate behaviours are observed with the appropriate techniques. These abilities should in no way be seen as inferior to those taught in training programmes. The emotional and communicative capacities of people with profound handicap are extremely valued by parents and carers. They represent, in essence, the *personality* of the individual. The more we discover of the world of infants, too, the more we are beginning to appreciate the primary role of these abilities in development.

I began this thesis with a quotation which comes from an address given by Edouard Seguin at the inauguration of the first residential hospital for people with a mental handicap in America. It has an optimistic tone, perhaps too patronizing for our times, but the philosophy it represents - that the able members of society have a responsibility to care for the less able to the best of their ability - is as important today as it was then. Great progress has been made towards this aim, and since this speech was given more has probably changed in the lives of people with a mental handicap in the last twenty years than in the previous eighty. In fact, times have changed so rapidly that the achievement Seguin was commemorating is now seen as undesirable. It is now generally recognized that all individuals should have the opportunity to live in the community. Unfortunately, people with profound handicap pose some problems in the implementation of this policy. They require a great deal of care, and will always do so. Their lack of abilities have led some to wonder how much they would benefit from a move into the community. This research has gone some way in answering this question. It has shown that people with profound handicap are sensitive to their environment, and to the behaviour of people around them. Above all, it has shown that in order to provide appropriate care for people with profound handicap, we have to be aware of what they are like and how they behave, both as a group and as individuals.

I would like to conclude with another comparison with the field of infant research. It has become a cliché that modern research into infant development has dispelled the notion that infants live in a world of 'booming, buzzing confusion', and replaced it with a view that sees infants as remarkably complex, active and able individuals. In short, infants are now recognized as people. It may be that the more research that is directed at understanding the behaviour of people with profound handicap, the more we will dispel the image of a 'vegetative existence' and replace this with an appreciation of the capacities that they possess, and the more, too, we will see them as people.



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## Appendix I. A Review of Journal Articles Referring to the PMH: 1974-1988

Main author, year of publication, and a summary of each paper is given. Books and edited conference reports are not included. All articles are reviewed except those on behaviour modification, where a selection is given. Papers marked with ' \* ' do not refer to the PMH directly, but are useful for background information.

### CLASSIFICATION

Cleland (1980)	iq's and aetiologies in different institutions
Durham (1985)	stanford-binet iq's for pmh
Hotte (1984)	pmh programming: classification
Burd (1988)	pervasive developmental disorder: classific
Switzky (1982)	problems in classification: pmh/smh differences
Rago (1977)	subtypes: of pmh
McLaren (1986)	subtypes: adaptive behaviour scale: subgroups
*Zigler (1984)	definition/classification of mh
*Cleland (1979)	problems: mislabeling and replication

### EPIDEMIOLOGY

#### *General*

Mclaren (1987)	epidem: review of recent data
*Fryers (1987)	issues in epidemiology
*Tomkiewicz (1974)	difficulties in statistical studies
*Gustavson (1977)	epidem & aetiology: Sweden, children
*Abramowicz (1975)	epidem: review of community studies
*Kushlik (1973)	epidem: Wessex
*Elwood (1981)	epidem: Northern Ireland
*Mallon (1983)	epidem: Northern Ireland
*de Almeida (1982)	epidem: Portugal, children/urban
*Rantakallio (1986)	epidem: Finland, children
*Zucman (1982)	epidem: France, children
*Adamovic (1985)	epidem: Yugoslavia, children
*Mao (1979)	epidem: China

#### *Epidemiology of Related Disorders*

Sadowsky (1985)	visual impairment in 1 regional centre
Zoller (1985)	auditory impairment: prevalence
James (1986)	psychiatric/behaviour disorders: in older mh
Ruedrich (1985)	psychiatric disorder: depression in mh
*Myers (1987)	aud impairment: related characteristics
*Shah (1982)	autism: prevalence in mh
*Wing (1979)	impairments in social interaction: epidem
*Sovner (1983)	psychiatric disorder: review in mh
*Groden (1982)	behaviour/emotional problems in mh

#### *Aspects of Epidemiology*

Simila (1986)	mortality of mh children
Rago (1981)	mortality and important events
Balakrishnan (1976)	life expectancy of mh
Evans (1985)	canadian indians in institutions
Achterberg (1978)	relationship of mh/cancer
*Colodey (1982)	disability in the third world

## AETIOLOGY

*Genetic*

Kerr (1986)

retts syndrome workshop

Kerr (1987)

retts syndrome 'hands &amp; minds'

Carrel (1973)

chromosome survey of mh

Warter (1977)

cytogenetic study

Pueschel (1987)

klinefelter syndrome/fragile x

*Metabolic Disorders*

Hollis (1983)

serum immunoglobulin

Chanowitz (1985)

thyroid and vitamin supplement and iq

Hestnes (1987)

secondary cystathioninuria

*Infections/Intoxications*

Reid (1980)

herpes simplex virus and smh

Lane (1984)

tuberous sclerosis

*Perinatal Causes*

\*Rantakallio (1985)

at risk/low birthweight: prognosis

*Associated Handicaps*

Neill (1986)

epileptic/psuedo-epileptic seizures

Holmes (1983)

epilepsy/abnormal behaviour: use of eeg

Ruedrich (1987)

depression: adrenocortical function

Reid (1987)

depression: flexion deformities/cytogenetics

*Biology of Mental Handicap*

\*Cowrie (1986)

neuropathology in mh

Katagiri (1988)

increases in auditory brainstem response

## PMH GENERAL

*Issues*

Ulciny (1985)

assessment of ineducability

Westling (1985)

differences in teaching smh and pmh

Walker (1985)

realities of institutional behaviour management

Grubb (1987)

no more blacks than whites in pmh pop

Spencer (1976)

new admissions to mh hospitals

Lawrence (1977)

effects of climate on mh behaviour

Jacobson (1985)

health status of smh and institutionalised

Tompsonowski (1985)

effects of exercise on s/pmh

Kaufman (1985)

effects of tempo variation on behaviour

Levinson (1981)

mh and stigma

Hardman (1978)

euthanasia and pmh

D'Onofrio (1980)

contact between residential mh and parents

Townsend (1976)

experimental preadmission programme

Kelly (1986)

obesity levels in mh

Mulholland (1985)

cardiovascular responses of pmh

Sharma (1977)

language of the mh

Walsh (1987)

characteristics of mh in community

\*Zigler (1969)

development/difference theories of mh

*Research Issues*

Gannon (1983)

ecological validity in studies: review

Mansell (1985)

time sampling and measurement error

Appell (1974)

parent/professional ratings of developmental tasks

Barton (1983)

naturalistic observation: effects on staff

\*Brooks (1977)

ecological validity

\*Brinker (1981)

reliability in early communication studies



## ASSESSMENTS

Whiteley (1986)	use of the bayley scales
Kahn (1976)	use of the uzgiris & hunt scales
Lambert (1979)	cognitive scale
Lambert (1979)	cognitive profiles of pmh on uzgiris-hunt
Muller (1978)	psychodiagnostic procedures
Cole (1985)	graded multidimensional scoring
Glenn (1983)	automated system for assessment
Smeets (1980)	scalogram analysis of behaviour strategies
Holmes (1982)	disability assessment schedule
Irvin (1984)	vocational assessment
Annis (1978)	social age scores
Hermanson (1977)	measuring adaptive functions
Aterianus (1976)	evaluating adaptive behaviours
Balthazar (1976)	sum of adjusted behaviour
Kenworthy (1978)	assessment of social competence (PAC)
Cirrin (1985)	communicative assessment
Zweiban (1977)	manual expression (Illinois test)
Deckner (1982)	Rimland e-2 assessment of autism
Laufer (1975)	behaviour maturity checklist
Aman (1985)	aberrant behaviour checklist
Aman (1987)	factor structure of "
Westling (1981)	inter-rater reliability of TARC
Rotatori (1978)	Slosson intelligence test: usefulness
Rotatori (1978)	Slosson int test: quick screening
Granger (1987)	dyskenesia exam: cooperation and assessment
Goetz (1982)	sensory assessment
Rogow (1978)	blind: assessment
Wolcock (1985)	deaf: assessment by operant tracking
Wyatt (1978)	deaf: hearing test
Heyer (1986)	deaf: assessment by music conditioning
Benham (1985)	deaf: assessment by 3 procedures
Cathey (1985)	deaf: bivariate plotting
Givens (1983)	deaf: assessment by acoustic reflex
Silva (1978)	deaf: assessment by preference for pure tone/speech
Gans (1983)	deaf: aud response behaviour/observation
*Snyder (1981)	infants: communication abilities
*Seibert (1987)	infants: social/communication skills
*Seibert (1982)	infants: social/communication scales
*Brinker (1982)	infants: discovering competent infants

## PROVISION OF SERVICES AND PLANNING

- Vitello (1974) normalization  
 Speck (1978) international advancement of pmh  
 Hardman (1987) transition from school to adult life eg Utah  
 Miller (1978) s/pmh = least restricted environment? eg Illinois  
 Howell (1980) resident care eg Somerset  
 Lockyer (1986) re-assessing services for mh  
 Martin (1974) future for s/pmh  
 McDonnell (1985) parents perspective of future needs  
 Elisabeth Ludeman Centre (1975) community oriented centre  
 Salisbury (1985) characteristics of residential children  
 Dailey (1974) staff: behaviour and attitudes to mh  
 Wallace (1983) staff: work preference  
 Marozas (1980) staff: motivation for job acceptance  
 Silver (1984) staff: attitudes and job satisfaction  
 Browner (1987) staff: stress/social support  
 Escudero (1982) staff: perception of teachers responsibility  
 Fabry (1978) teaching foster grandparents  
 Bailey (1983) individual participation in multi-disc team  
 Cleland (1977) institutional architecture  
 Ronning (1983) treatment goals for s/pmh  
 Adams (1982) referral advice from physicians  
 Uslan (1979) orientation and mobility for s/pmh blind  
 Altman (1976) research needs with s/pmh  
 Heller (1982) social disruption of relocation  
*Vocational Skills*  
 Dahl (1982) maximizing vocational opportunities  
 Revell (1978) vocational evaluation of s/pmh  
 Snart (1983) future directions in vocational training  
 Misawa (1987) vocational adjustment of mh  
 Gordenchuk (1987) work therapy  
 Wehman (1985) transition from school to work in smh  
 Bellamy (1975) habilitation of s/pmh: competence  
 Wade (1978) improving job design for mh  
 Jacobs (1976) pmh as corn gleaners  
*Residence and Institutionalization*  
 Rawlings (1985) effects of different residences: lifestyles  
 Rawlings (1985) effects of different residences: behaviours and skills  
 O'Neil (1985) effects of different residences: activities and skills  
 Felce (1986) effects of different residences: adaptive behaviour  
 Felce (1986) effects of different residences: ecobehavioural analysis  
 Felce (1985) effects of different residences: physical setting  
 Mansell (1984) effects of different residences: activity levels  
 Close (1977) effects of different residences: group home study  
 Shalik (1987) effects of different residences: cluster homes  
 Silverman (1986) effects of different residences: adaptive behaviour changes  
 Witt (1981) effects of different residences: adaptive behaviour changes  
 Shrubsole (1984) effects of different residences: incontinence  
 Ellis (1981) institutionalization effects: short-term  
 Ohwaki (1978) institutionalization effects: intellectual functioning  
 Philips (1979) institutionalization effects: deterioration in language

## EDUCATION AND PLANNING

- Edgar (1985) special education children: identification and numbers  
 Haring (1975) educational services  
 Wilton (1984) needs and services for preschool mh in NZ  
 Smith (1974) case for special class  
 Luckey (1974) pmh: challenge for special education  
 Rago and Cleland (1978) future directions in education of pmh  
 Sontag (1973) considerations for serving smh in schools  
 Sontag (1979) education of s/pmh and doctrine of limitations  
 Sontag (1981) rhetoric and responsibility  
 Burton (1978) focus of responsibility in education of s/pmh  
 Burton (1979) further thoughts on education of s/pmh  
 Burton (1979) education of s/pmh: child or concept?  
 Burton (1979) bandwagons and education of s/pmh  
 Burton (1981) analysis and discourse of education of s/pmh  
 Burton (1981) teachers responsibility in what to teach  
 Tawney (1981) issues in education of s/pmh  
 Green (1986) improving classroom service  
 Mackowiak (1978) developmental guide for education of s/pmh  
 Somerton (1978) education planning system for s/pmh  
 Barton (1986) effectiveness of extended year  
 Theunissen (1981) fostering esthetic sensibilities  
 Icabone (1982) least restrictive environment for s/pmh  
 Binford (1981) comprehensive analysis of special education  
 Frith (1981) parent/paraprofessionals in programs  
 Hawkins (1981) parental observations on education of s/pmh  
 Meyers (1987) ": home and family variables  
 Thomason (1980) educating s/pmh: side by side approach  
 Westling (1982) arrangements for teaching  
 Milne (1979) teacher training: competencies needed?  
 Stainback (1976) teacher training  
 Stainback (1977) teacher training: accountability  
 Brakman (1985) human rights in public school  
 Wehman (1978) curricula: review  
 Kiernan (1977) curricula: for pmh multi-handicapped  
 McCormick (1984) curricula: for smh preschoolers  
 Bates (1981) curricula: for an appropriate education  
 Davis (1973) curricula: role of educator  
 Meyen (1976) curricula: problems  
 Jacobson (1987) curricula: individual program goal content  
 Cooley (1986) curricula: functional and appropriate  
 Dana (1986) curricula: rehumanization  
 Erin (1986) curricula: for visually handicapped

## ASPECTS OF CARE

Sturmey (1984)	methods for organizing training
Felce (1984)	systematic individual teaching for s/pmh
Stephens (1985)	effects of individual program planning
Miller (1978)	spatial change and behaviour
LaMendola (1987)	foundation care treatment model
Hooper (1985)	simple environmental redesign
Murphy (1978)	improved physical/social environment effects
Murphy (1975)	improved ward conditions & self-help skills
Norton (1975)	neurodevelopment and sensory integration
Leath (1974)	sleep reversal
Ohwaki (1988)	feeding multi-handicapped
Ayres (1987)	effect of music on feeding
Korabek (1981)	improving feeding through staff supervision
Hendrikson (1985)	dining arrangements and behaviour
Wilson (1984)	normalization of mealtimes
<i>Staff and the Effects of Organization</i>	
Mansell (1982)	increasing staff ratios
Burch (1987)	staff management: general improvement
Parsons (1987)	staff management: functional tasks
Reid (1985)	staff management: appropriate tasks
Coles (1981)	staff management: activities
Burgio (1983)	staff management: interactions
Byrd (1983)	staff management: socialization
Kissel (1983)	staff management: self-help skills
Ford (1984)	staff management: teaching skills
Page (1982)	staff management: pyramidal training
Spreat (1987)	effects of modular play unit
Ruttimann (1986)	integration facilitator
Spangler (1983)	unit play manager
Mansell (1982)	room manager
<i>Leisure</i>	
Wehman (1976)	leisure activities curriculum
Wehman (1978)	leisure activities and smh: research
Wehman (1978)	leisure skill programming
Wehman (1978)	leisure activities: different environments
Saxby (1986)	use of shops and cafes by s/pmh
Nietupski (1983)	review of leisure skills of s/pmh
Crisp (1984)	toys: evaluation
Murphy (1986)	toys: design
Wehman (1976)	toys: selecting play materials
Roberts (1976)	toys: instructional material for s/pmh
White (1976)	toys: stimulus box
Realson (1988)	toys: leisure materials
Bennet (1988)	toys: inflatable

*Therapies*

Giangreco (1986)  
 Dura (1988)  
 Eydenberg (1986)  
 Henley (1986)  
 Oldfield (1983)  
 Coates (1987)  
 Wolpow (1976)  
 Monfils (1985)  
 Paisee (1974)  
 Bertoli (1985)

*Pharmacology*

Fox (1986)  
 Aman (1985)  
 (1986)  
 Burgio (1985)  
 Singh (1984)  
 Towns (1984)  
 Arnstein (1986)  
 Gowdey (1985)  
 Aman (1985)  
 Aman (1986)  
 Reid (1981)  
 Albert (1977)  
 Aman (1984)  
 Anderson (1984)  
 Aman (1982)  
 Durand (1982)  
 Aman (1988)  
 \*Fishbacher (1987)

integrated therapy: effects  
 integrated therapy: for self-injury?  
 art therapy: for s/pmh  
 art therapy: for emotional handicaps  
 music therapy: for pmh  
 music therapy: functional?  
 music therapy: effects of social skills approval  
 theme-centred work with mh  
 psychotherapy: drawings of pmh  
 using fairy tales with the pmh  
  
 prevalence: in school district  
 prevalence: drug patterns in 1 city  
 prevalence: antipsychotic drugs  
 evaluation: medications  
 evaluation: behaviour monitoring  
 evaluation: reliability of observations  
 studies: carbamazepine effects/ocular changes  
 studies: phenothiazine derivatives/ocular changes  
 studies: methylphenidate/withdrawal  
 studies: imipramine/depression  
 studies: carbamazepine/overactivity  
 studies: SCH-12679/ aggression  
 studies: chlorpromazine/ stereotyped behaviour  
 studies: haloperidol/ infantile autism  
 studies: methylphenidate/ stereotopy? no effect  
 studies: behaviour/pharmacology/ self-injury  
 studies: thioridazine/stereotopy  
 prevalence: prescribing in a mh hospital

## COGNITION

Ellis (1982)  
 Ellis (1982)  
 Butcher (1977)  
 Meador (1984)  
 Kelman (1986)  
 Terada (1988)  
 Soraci (1986)  
 Garcia (1974)  
 \*O'Connor (1987)

learning, memory and transfer  
 recognition memory using novelty  
 recognition memory for colours and faces  
 visual discrimination and effects of colour  
 habituation and generalization of habituation  
 visual receptive processes  
 sensitivity to aud relational information  
 perception of depth  
 cognitive psychology and mh



## TRAINING AND BEHAVIOUR MODIFICATION

*Reviews*

- Stainback (1983) a review of research on educability of pmh  
 Foster (1974) behaviour modification in behaviour training of s/pmh  
 Singh (1983) social skills training  
 Konarski (1985) self-help research: a quantitative review  
 LaGrow (1984) intervention into stereotypic responding  
 Williams (1978) behaviour principles in teaching pmh  
 Presland (1982) a guide to teaching motor skills  
 Clarke (1987) learning and training since 1957

*Issues*

- Hogg (1981) issues in training & evaluation of behaviour mod  
 Bailey (1981) limiting conditions of habilitation  
 Glover (1978) sensory stimulation techniques  
 Clark (1978) operant vs sensory integrative methods  
 Safir (1981) operant vs traditional treatment  
 Dunst (1985) response contingent learning in pmh  
 Cottam (1985) effectiveness of conductive education on pmh  
 Ranieri (1984) 1:1 vs 1:3 instruction  
 Storm (1978) small group vs individual instruction  
 Bourland (1988) group vs individual inst: multi-behaviour comparison  
 Repp (1981) accountability system in behaviour programs  
 Greene (1978) measuring client gains from programs  
 Song (1974) analysis of behaviour during feeding training  
 McGavern (1972) modelling behaviour in echopraxic mh  
 Kauffman (1976) imitating children during imitation training

*Reinforcers*

- Rotatori (1979) identifying reinforcers: indirect technique  
 Green (1988) identifying reinforcers: staff opinion/assessment  
 Pace (1985) identifying reinforcers: assessment  
 Wacker (1985) identifying reinforcers: microswitches  
 Nunes (1980) identifying reinforcers: progressive ratio  
 Metzler (1974) reinforcers: music to increase imitation  
 Kupperschmitt (1982) reinforcers: music  
 Saperston (1980) reinforcers: music vs juice  
 Fehr (1979) reinforcers: visual/auditory/vibratory  
 Remington (1977) reinforcers: auditory  
 Glenn (1984) reinforcers: auditory  
 Haskett (1978) reinforcers: sensory stimulation  
 Wolber (1987) reinforcers: tangible vs social  
 Capron (1983) reinforcers: animals

## EXAMPLES OF BEHAVIOUR MODIFICATION STUDIES

Pancsofar (1985)	generalization effects
Wacker (1985)	generalization and maintenance of skills
Day (1987)	skill acquisition: prompting
Lyon (1984)	scan training/matching
Richmond (1983)	training size discrimination
Bell (1984)	training position discrimination
Nigl (1980)	behaviour training
Berdine (1977)	adaptive behaviour training
Morris (1977)	social skills: eye contact
Giangreco (1982)	social skills : imitation
Wehman (1978)	social skills : free play skills
Zucker (1980)	social skills : eye pointing
Murphy (1985)	social skills : increasing toy play
Horner (1985)	skills: street crossing
Rae (1985)	skills: fire safety training
Schleien (1981)	skills: leisure skills
Lagomarcino (1984)	skills: leisure dance instruction
James (1985)	motor skills: aud/ vestibular stimulation effects
McNeill (1986)	motor skills: memory theory
Feldstein (1987)	motor skills: walking behaviour
Colwell (1973)	self-help skills: evaluation
Bettison (1976)	self-help skills: toilet long term effects
King (1975)	self-help skills: at home
Smith (1981)	self-help skills: bladder during toilet train
Lambert (1974)	self-help skills: eating habits
De-Kock (1984)	self-help skills: mealtime behaviour
Bronder (1980)	self-help skills: feeding/play
Antonelli (1981)	vocational: program
Schepis (1987)	vocational: group instruction of skill
Flexer (1982)	vocational: work productivity
Renzaglia (1978)	vocational: work production
Bellamy (1978)	vocational: workshop supervision
Abbas (1978)	vocational: industrial tasks
Dolan (1987)	maladaptive behaviour: screen for screaming
Drabman (1978)	maladaptive behaviour: icing for finger chewing
Roberts (1979)	maladaptive behaviour: overcorrection for stereo
Greer (1985)	maladaptive behaviour: toy play for stereo
Williamson (1983)	maladaptive behaviour: sensory extinction
White (1985)	maladaptive behaviour: disruptive behaviour
Mace (1986)	maladaptive behaviour: severe pica
Barton (1985)	maladaptive behaviour: differential reinforcement for stereo
Cobben (1976)	maladaptive behaviour: stereo: behaviour approach

## BEHAVIOUR

Berkson (1977)	behavioural research on s/pmh 1955-74
Vyse (1984)	ecobehaviour assessment of classroom
Green (1986)	naturalistic observation: classroom
Repp (1983)	naturalistic studies: density & behaviour
Barton (1981)	" : stereo/handicap/pop density relationships
Barton (1982)	" : effects of mh behaviour on other mh and staff
Eyman (1987)	life span development of inst & non-inst
Landesman-Dwyer (1979)	pmh/pmh: affiliation and friendship in mh
Pechachek (1973)	self recognition in pmh
Harris (1977)	self recognition in pmh
Altman (1972)	social responsivity in pmh
Bailey (1977)	threatening stare response latencies
Paslawskyj (1980)	dominance and territoriality
Rago (1977)	eye gaze and dominance hierarchy
Rago (1978)	touching frequency and status
Rago (1978)	territoriality and aggressive behaviour
Rago (1978)	effect of increased space on social skills behaviour
Cleland (1978)	tool use
Soper (1987)	handedness distribution
Lewis (1981)	ultradian rhythms in stereotypy behaviour
Pasquasy (1977)	sexuality and procreation in pmh
Uno (1975)	preferences for male/female voices
Dorow (1982)	effect of auditory/sung/spoken stimuli

## BEHAVIOUR PROBLEMS

Reid (1978)	behavioural syndromes & cluster analysis
Reid (1984)	" : follow up
Benson (1985)	behaviour disorders & mh: associations of age etc
Cleland (1976)	daybook analysis of disruptive behaviours
Wieseler (1985)	functional taxonomy of stereotypy & self-injurious behaviour
Wehman (1979)	teachers perceptions of behaviour probs
Matson (1986)	review: treatment research on aggressive/disruptive behaviour
Gorman-Smith (1985)	review: treatment research on self-injury & stereotypy
Peniston (1975)	reducing behaviour problems in s/pmh
Durand (1987)	reducing severe behaviour problems: technical assistance
Slifer (1986)	reducing multiple behaviour probs and ass
Richmond (1983)	reducing destructive behaviour: unrelated practice
Marks (1981)	reducing object destruction: device
<i>Stereotypy</i>	
Dura (1987)	prevalence among institutionalised nonambulant
Spindler (1980)	review of stereotypy behaviours
Berkson (1983)	relationship with age
Sturmey (1988)	functional analysis of multi aberrant responses
Cavalier (1980)	intervention in stereotypy
Pohl (1976)	experimental control of rhythm
Mace (1988)	reduction through alternative leisure behaviour
Buyer (1987)	stimulation and control in stereotypy
Lewis (1984)	effects of auditory tempo changes
Sramka (1975)	changes after hypothalamus operation
MacLean (1985)	blink rate: dopamine involvement in stereotypy?
Nakamura (1982)	teaching sensorimotor & reducing stereotypy

*Self-Injury*

Rojahn (1984)	prevalence & staff agreement
Oliver (1987)	prevalence: total pop study
Griffin (1986)	prevalence & circumstances
Spreat (1983)	patterns of injury in institutionalised mh
Singh (1980)	clinically significant vs therapeutic control
Noel (1984)	composite/cumulative approach to treatment
Taylor (1986)	reduction through visual/vibratory stimulation
Beckwith (1986)	failure of naloxone to reduce self injury
Wells (1983)	reduction using sensory integrative techniques
Rojahn (1980)	ecological assessment of self-protective device

## TRAINING OF COMMUNICATION SKILLS

Kahn (1981)	non-vocal: sign vs verbal language training
Kahn (1977)	non-vocal: manual vs oral language training
Kiernan (1981)	non-vocal: strategy for research
Yoder (1983)	non-vocal: intervention issues
Hodges & Deich (1978)	non-vocal: teaching premack system to pmh
Deich & Hodges (1982)	non-vocal: teaching premack system to pmh
Hodges (1984)	non-vocal: graphic symbol vs manual sign
Sternberg (1985)	non-vocal: teaching pre-language signalling
Sternberg (1985)	non-vocal: developing co-active imitation
Sternberg (1987)	non-vocal: developing primitive signalling
Gola (1982)	non-vocal: group contingency procedure
Hobson (1979)	non-vocal: sign learning and pmh
Haskett (1977)	non-vocal: training instrumental symbolic communication
Ferguson (1975)	non-vocal: manual language with s/pmh
Richardson (1975)	non-vocal: sign language for s/pmh
Carrier (1974)	non-vocal: noun training
Schepis (1982)	non-vocal: increasing manual signing
Egan (1985)	non-vocal: signing using microcomputers
Thomas (1981)	non-vocal: computer based language training
Duker (1985)	non-vocal: increasing signs in natural environment
Lombardino (1983)	non-vocal: short term intervention program
Faw (1981)	non-vocal: involving staff in development/maintenance of signs
Booth (1978)	receptive: early training for s/pmh
McCuller (1984)	receptive: action-object verbal instruction
Stiefel (1973)	receptive: instruction following behaviour
Stiefel (1974)	receptive: transfer stimulus from motor to verbal
Witt (1981)	receptive: teaching to respond to directives
Kazdin (1975)	receptive: training to obey instructions
Davis (1978)	vocal: programming language
Wehman (1978)	vocal: language instruction: 2 years of data
Kahn (1984)	vocal: cognitive training and referential speech
Phillips (1973)	vocal: para-professional teachers and language programs
Wheeler (1973)	vocal: attendants build verbal repertoire
Barton (1973)	vocal: operant conditioning of social speech
Brody (1977)	vocal: operant vs sensory integration vocalization
Bates (1982)	vocal: table game in language instruction
Carasa (1983)	vocal: increase in spontaneous vocalisations
Richmond (1983)	vocal: transfer control of verbal labels
Butz (1973)	vocal: developing verbal imitative behaviour
Garcia (1980)	vocal: teaching generalized speech

## INTERACTION

*Interactions Between PMH and Staff*

- Kawada (1986) pmh communication: needs  
 Wright (1974) pmh/staff interactions  
 Hermanson (1977) pmh/staff interactions  
 Felce (1987) pmh/staff interactions: behaviours staff respond to  
 Houghton (1987) opportunities to express preferences  
 Reuter (1980) social milieu of treatment centre  
 Goode (1976) ascertaining choice with deaf-blind  
 \*Veit (1974) mh/staff interactions

*Mother-Infant Interaction in PMH*

- Blacher (1984) intervention: attachment and smh  
 Michaelis (1978) early linguistic environment  
 \*Yoder (1988) mothers attributions of communication to mh infants  
 \*Odom (1988) intervention: early intervention

*Attempts to Increase Interaction*

- Mayhew (1978) social environment  
 Porterfield (1980) improving social environment  
 Sturmey (1982) methodological note on porterfield  
 Harris (1974) aide-resident ration  
 Peterson (1979) teacher prompts  
 Cone (1978) development and maintenance social interactions  
 Horner (1980) environmental enrichment  
 Repp (1981) pmh/staff interactions: different size residence  
 Thomas (1986) pmh/staff interactions: different size residence  
 Ivancic (1981) supervision programme for social skills interact  
 Singh (1987) training independent social play  
 McBrien (1980) room management  
 Peck (1985) increasing social control in autistic/smh  
 Bigelow (1974) pmh/staff interactions: in behaviour modification  
 Cole (1987) pmh/children interactions: age discrepancy  
 Cole (1986) pmh/children interactions

## DEVELOPMENT

- Switzky (1979) implications of developmental model  
 Rogers (1977) characteristics of cognitive development of pmh  
 Kahn (1979) applications of piaget to s/pmh  
 Kahn (1983) sensorimotor/adaptive behaviour development of s/pmh  
 Silverstein (1975) 2 sets of piagetian scales with s/pmh  
 Silverstein (1981) stability of piagetian scales with s/pmh  
 Silverstein (1982) test of similar sequence hypothesis  
 Silverstein (1982) cognitive development of s/pmh  
 Narukawa (1982) factor analytic study of development in s/pmh  
 Macpherson (1988) sensorimotor intelligence in smh  
 Butterworth (1984) sensorimotor intelligence in s/pmh  
 Lobato (1981) sensorimotor func & pre-linguistic communication in s/pmh  
 Webb (1979) sensorimotor training & effects on pmh  
 Wohlheuter (1975) longitudinal development of object concept in mh  
 Samaras (1975) reinforcement of cooperation between pmh  
 Whittaker (1980) development of symbolic play in pmh  
 Glenn (1984) nursery rhymes and language acquisition  
 \*Snyder (1978) communicative/cognitive abilities in sensorimotor period



## Appendix II. Piaget's Theory of Development

Piaget's theory of development has been extremely influential in psychology, and most developmental studies are rooted firmly in a Piagetian tradition. A similar situation prevails in considerations of the development of the mentally handicapped. It is therefore essential to have a grasp of the main points of the theory. In this appendix, a description of the stages of development described in the theory are given, together with an explanation of some of the terms used by Piaget.

**The child:** considered to be actively engaged in constructing and understanding the world from birth. The development of understanding is achieved through active intellectual construction, later from language but firstly through perception of the world and physical movement directed to it.

### **Stages in the development of cognition :**

1. Sensorimotor (birth to 2 years)
2. Pre-Operational (2 to 7 years)
3. Concrete Operations (7 to 9 years)
4. Formal Operations (11 to 15 years).

**The Sensorimotor stage:** the developmental period of most interest in the study of PMH. It has six sub-stages:

- I. Exercising ready-made Sensorimotor reflex schemes (0-1 month)
- II. Primary circular reactions (1-4 months)
- III. Secondary circular reactions (4-8 months)
- IV. Coordination of secondary schemes (8-12 months)
- V. Tertiary circular reactions (12-18 months)
- VI. Internalization of schemes and invention of new means through mental combinations (18-24 months)

**Domains of development:** Development is considered to occur across several domains, with stages marking the changes in development. Attainment of the various stages and sub stages is deduced from behaviour on developmental tests which demonstrates the mental processes being used. Particular processes typify a particular stage. In Sensorimotor development there are six major domains of development, all closely related:

- i) **Object permanence** (a very young child is believed to be egocentric - unaware of the separate existence of objects or others - and has to develop the notion of the continued existence of objects when they are not being looked at. This is partially achieved by Sensorimotor stage IV.)

- ii) **Spatial understanding** (similarly to i, space is presumably seen only in terms of it's relationship to the infant)
- iii) **Conception of time** (learnt through activities with objects)
- iv) **Intentional behaviour and means-end relations** (goal-directed behaviour observed with objects in stage IV.)
- v) **Causality** (towards end of first year, child views self and others as causes of events)
- vi) **Imitation** (proceeds through several stages during the Sensorimotor period, beginning with the imitation of others imitations of their own acts, ending with the ability to imitate non-human absent objects. Aspects of this development are thought to be important for language)

**Sequential order of stages:** although there is some slight variation in the age at which a stage may be achieved, the order through which stages and sub-stages are passed is fixed and unchangeable. For example: a child searching for and uncovering an object that has been hidden from view is assumed to be demonstrating the mental process of 'object permanence' - i.e. that he knows that the object continues to exist even though he can no longer see it. This places him at the 'Co-ordination of secondary schemes' Sensorimotor stage IV, usually 8 to 12 months. Piaget believed that this stage had to be passed before the child progressed to later stages, e.g. stage VI, (internalization of schemes), typified by the child imitating a mothers actions after the event.

**Schemes:** Piaget describes the developmental process in terms of 'schemes'. These refer to the 'tactics' or behaviour patterns that the infant has in order to understand the world (e.g. mouthing, holding, shaking, dropping an object). These are modified through experience. Through the development of schemes, which occurs against the background of the development of play, the infant learns the properties of objects and people and is prepared for further development.

**Schemes for relating to objects:** change from the first reflexive (innate) schemes of stage I, are indiscriminately applied in stage II, are beginning to be intelligently applied by stage III, are coordinated action sequences in stage IV, trial and error is used in stage V, and in stage VI mental representations of previous acts are used for deductions. Infants are not born with an understanding of the world of objects, and this has to be constructed in interaction with the environment.

### Appendix III. A Theory of Early Development Based on Emotional and Communicative Developments

Piagetian theory has long been dominant in developmental psychology, but an area in which particular advances has been made in recent years is in the emotional and communicative development of infants. Discoveries made in this field are hard to reconcile with traditional Piagetian theory, which emphasizes cognitive development, yet social aspects may prove to be of the utmost importance in understanding the development of normal infants and of the PMH.

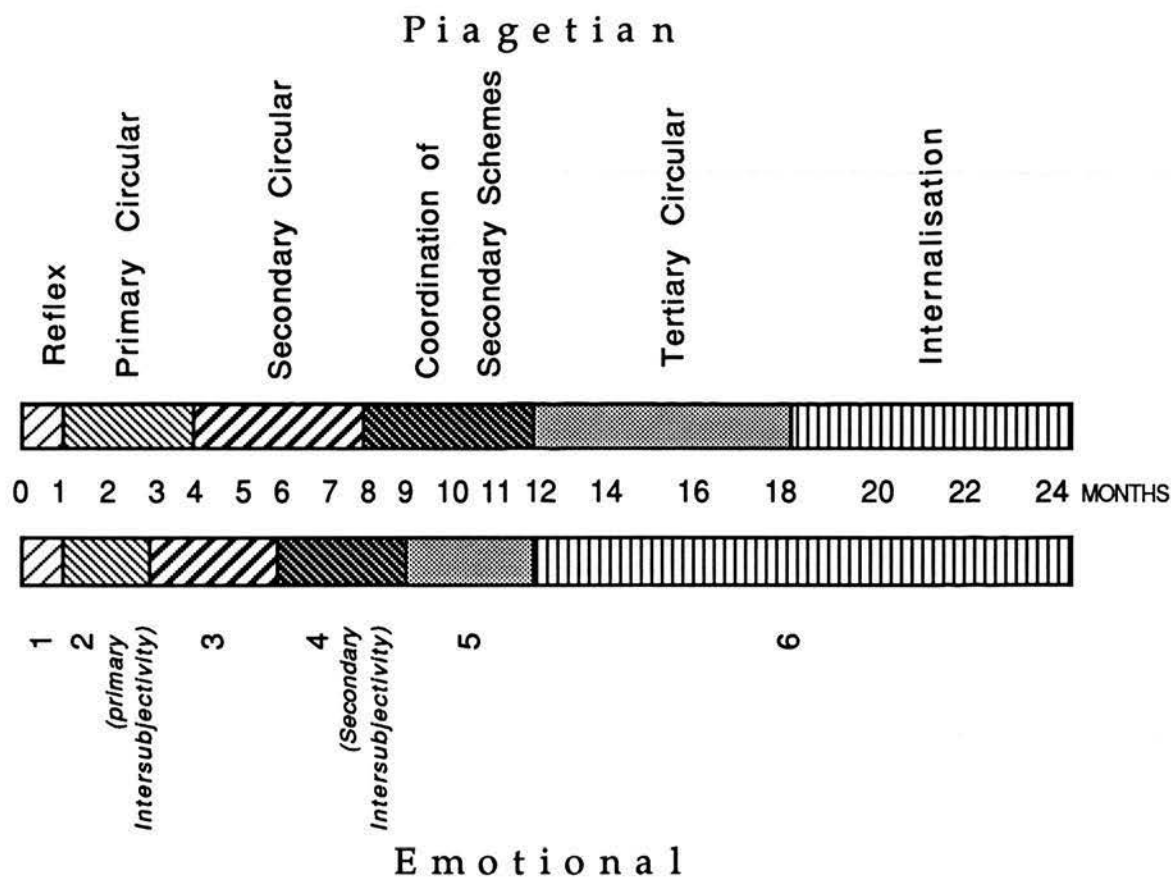
Concentrating on emotional and communicative development in the first two years - particularly in the first year - there is a wealth of valuable information which both compliments and contradicts Piagetian theory. Using this research, I have devised a framework for emotional and communicative development over the first two years This is presented in table form over three pages in this appendix.

This table covers the same period of time as that of the 'Sensorimotor' stage in Piagetian development. This stage is divided into six substages, and I have also divided the 'Emotional/Communicative' framework into six substages which seem to represent significant changes in behaviour. The relationship between these stages and the stages of Piagetian theory are shown in Table A3.1 (over).

As can be seen, I have not named any of the emotional/communicative stages, but stage one corresponds to the period sometimes referred to as 'primary intersubjectivity', and stage four can similarly be known as 'secondary intersubjectivity'.

Comparing the two sets of stages, it can also be seen that there are more emotional / communicative stages in the first year, indicating the importance of this period for social development.

Table A3.1 The Relationship Between the Stages of the Piagetian and Emotional/Communication Based Developmental Frameworks.



The framework presented in the following table divides infant development into three separate areas, and also includes a description of changes in the mothers behaviour. The areas covered are:

'self'	development of self awareness
'others'	development of communication/interaction
'objects'	development of understanding of objects
'mothers behaviour'	changes in mothers behaviour to the infant

This table summarizes all psychological research relevant to the emotional and communicative development of infants. The sources consulted in its compilation include: Bullowa (1979); Stern (1979, 1985); Trevarthen (1979, 1982, 1983, 1985, 1986); Trevarthen, Murray and Hubley (1981); Field and Fox (1985); Dunn (1977); and Schaffer (1971, 1977).

<b>AREA: SELF</b>	<b>1: 0-1 month</b> <ul style="list-style-type: none"> <li>* Internal rhythms regulate arousal/waking /sleeping; periods of alert inactivity.</li> <li>* Self synchrony in movements.</li> <li>* Sucking response innate, complex, and internally organized; has a burst-pause pattern, coordinated with breathing etc.</li> <li>* Identifies invariants of experience.</li> <li>* Spectrum of human emotions present at birth (responds with the appropriate expression and feelings).</li> <li>* Predisposition to order experience (sees world as intensities, shapes, temporal patterns, hedonic tones).</li> </ul>	<b>2: 1-3 months (<i>primary intersubjectivity</i>)</b> <ul style="list-style-type: none"> <li>* Identifies invariants of self; regularities in: self agency (volition, proprioceptive feedback) self coherence (unity of locus) self affectivity (same emotion/different context) self history (motor/perceptual/affective memory)</li> <li>* No period of innate undifferentiation.</li> <li>* Identifies invariants of others: there are opportunities in the exaggerated vocal repetitiveness of the mother (baby talk).</li> <li>* Sense of self integrated in episodic memory.</li> </ul>
<b>OTHERS</b>	<ul style="list-style-type: none"> <li>* Imitation of simple facial gesture from birth.</li> <li>* Produces discomfort sounds: cries/fusses.</li> <li>* Consistent preferences in perception for human features, especially mothers.</li> <li>* Can recognize mother from sight, odour, sound of voice &amp; rhythm of movements.</li> <li>* Synchrony in movements to adult speech and movements (entrainment); periodicity of movements are compatible with those of adults.</li> <li>* Turntaking pattern in sucking behaviour similar to that seen in adult speech.</li> </ul>	<ul style="list-style-type: none"> <li>* Sustained periods of eye contact.</li> <li>* There is a speech-like pattern of communicative exchanges between infant and mother including speech-like turntaking and coaction.</li> <li>* Mutual regulation of exchanges based upon shared rhythm of movement: infant is active partner in dyadic communication.</li> <li>* Communicative expressions used: smiling, cooing, prespeech, facial expressions.</li> <li>* Emotional expression through face/voice/hands/ lip and tongue movements/posture/gesture.</li> <li>* Fear of strangers.</li> <li>* Produces comfort sounds: cooing/laughter.</li> </ul>
<b>OBJECTS</b>	<ul style="list-style-type: none"> <li>* Differentiation of sounds.</li> <li>* Amodal sensory transfer.</li> <li>* Reflex sucking.</li> <li>* Palmar grasp.</li> </ul>	<ul style="list-style-type: none"> <li>* Extends and turns neck when prone.</li> <li>* Mouths objects.</li> <li>* Sound localization.</li> <li>* Visual pursuit of object.</li> </ul>
<b>THE BEHAV- IOUR OF THE MOTHER</b>	<ul style="list-style-type: none"> <li>* Mother provides social contact, especially during feeding.</li> <li>* Provides stimulation but is sensitive to amount, kind and timing (infants state, the amount and type of stimulation which is suitable, and timing to fit in with infants state and responses).</li> <li>* Mother personalizes stimulation.</li> <li>* Provides physiological regulation; but also mutual regulation in feeding etc.</li> <li>* Provides variety/frequent responses.</li> <li>* Responds promptly to infants actions, fostering the development of contingency and effectance.</li> <li>* Attributes intention to infants actions.</li> </ul>	<ul style="list-style-type: none"> <li>* Mothers communicative expressions adapted to infant's interests: expressive movements and speech (baby talk) are regular, repetitive, simple exaggerated, rhythmic, &amp; playful - they are fun for the infant.</li> <li>* Responds to infants expressions.</li> <li>* Treats infant as another person.</li> <li>* Sensitive and subordinate to infants actions - behaviour is phased by infants actions (follows gaze, leaves gaps in speech for responses etc.).</li> <li>* Supportive of infant.</li> </ul>



<p>3: 3-6 months</p> <ul style="list-style-type: none"> <li>* Body awareness stimulated in play.</li> <li>* Can experience acute joy in play.</li> <li>* Sense of 'core' self fully integrated.</li> </ul>	<p>4: 6-9 months</p> <ul style="list-style-type: none"> <li>* Heightened self awareness: self conscious behaviour in front of mirror; play acts/ shows off by giving performances of favourite tricks.</li> <li>* Open to effects of enculturation.</li> <li>* Sense of 'subjective' self develops: awareness that self and others have minds.</li> <li>* Possibility of 'sharing' subjective states develops.</li> </ul>
<ul style="list-style-type: none"> <li>* Reduced levels of face to face contact.</li> <li>* Less interest in mother, more in environment.</li> <li>* Nature of play changes: becomes more vigorous</li> <li>* Increasing individuality and autonomy of purpose of infant within companionship of play.</li> <li>* Ritual sociodramatic forms of play in playful combat; if will thwarted, infant may protest/ defy/attack partner and show an aggressive or determined expression.</li> <li>* Infant can appear disinterested in mother.</li> <li>* Mother used as secure base from which to explore.</li> </ul>	<ul style="list-style-type: none"> <li>* Heightened awareness of others: anticipation of mothers actions; sensitive to mothers feelings; shares sense of humour with mother.</li> <li>* Acknowledges others approval/ &amp; interest.</li> <li>* Deliberate imitation of hand movements/ expressions/vocalizations/specific words and gestures.</li> <li>* Defence of attachment to mother (separation causes depression); heightened fear of strangers.</li> <li>* Appearance of rivalry/deceit/temper tantrums in play.</li> <li>* Playful expressiveness in games; can start games to amuse self or others; sometimes gives socio-dramatic performances understood by family and friends only (proto symbols).</li> </ul>
<ul style="list-style-type: none"> <li>* Aware of mothers hands and vocalizations mother makes when manipulating objects.</li> <li>* Coordination of reaching and grasping.</li> <li>* Observational learning (what others intend or feel); motivation for experience.</li> <li>* Actions made towards physical things.</li> <li>* Realization that actions cause events.</li> <li>* Problems of movement being solved and transforming experience of body/outside world.</li> </ul>	<ul style="list-style-type: none"> <li>* Serious attitude to objects (can get angry).</li> <li>* Can grasp object with two hands.</li> <li>* Can tear, shake, rotate, slide, swing, drop, (and observe) objects.</li> </ul>
<ul style="list-style-type: none"> <li>* Mother responds to changes in play with more vigorous play.</li> <li>* Vocalizations more complex/higher pitch.</li> <li>* Sings traditional nursery rhymes, chants, rituals &amp; games which have a beat/rhythm of interaction common to all cultures.</li> <li>* Musical qualities of communicative movement are highlighted.</li> <li>* Infant is excited to share in the development of a melody/action game.</li> <li>* Qualities of the mothers voice signal feelings.</li> <li>* Beat/rhythm/melody favours joint control of mood.</li> </ul>	<ul style="list-style-type: none"> <li>* Separation from mother causes depression.</li> <li>* Game playing important; mother sensitive to infants needs and moods; encourages infant.</li> </ul>

<p><b>5: 9-12 months (<i>secondary intersubjectivity</i>)</b></p> <ul style="list-style-type: none"> <li>* Development of sense of 'subjective' self continues.</li> <li>* Increase in sharing of subjective states with others; includes: <ul style="list-style-type: none"> <li>- sharing focus of attention</li> <li>- sharing of intentions</li> <li>- sharing of affective states (affect attunement).</li> </ul> </li> <li>* Infant aware of sharing; comes to expect it e.g. in affect attunement).</li> </ul>	<p><b>6: second year</b></p> <ul style="list-style-type: none"> <li>* Development of sense of 'verbal' self from 15 months.</li> <li>* Ability to mentally represent others actions and compare with own attempts.</li> <li>* Objective view of self develops (e.g. uses verbal labels to designate self - 'me', 'i').</li> <li>* Capacity for symbolic and fantasy play.</li> <li>* Use of words to describe thoughts etc.</li> </ul>
<ul style="list-style-type: none"> <li>* Development of human cooperative awareness: willingness to participate in joint tasks and comply with mothers instructions in object use</li> <li>* Aware that others possess intentions/feelings.</li> <li>* Produces word like sounds.</li> <li>* Assimilates conventional gestures into expressive repertoire; conveys wishes/denials/refusals/satisfaction etc. in accepted way.</li> <li>* Uses combinations of hand gestures/postures/vocalizations/appropriate facial expression.</li> <li>* Interest in others gestures &amp; utterances.</li> <li>* Utterances usually purposeful.</li> <li>* Emotional referencing of objects: (e.g. bad knife)</li> <li>* More interested in mothers directives in games.</li> <li>* Interest and pride in knowledge of convention.</li> <li>* Need for sensitive, affectionate, trusted partner.</li> </ul>	<ul style="list-style-type: none"> <li>* Understanding of speech develops: words used to signal awareness of a 'shared reality'.</li> <li>* Utterances and gestures coordinated with the attention of the mother.</li> <li>* Usually obeys mothers instructions, though may choose not to.</li> <li>* Will turn to mother to explain unfamiliar objects.</li> <li>* 2-4 words used with meaning.</li> <li>* Indicates excitement through fluent vocalizations and gestures.</li> <li>* Development of symbolic understanding: words understood to have meaning beyond the limits of time and space.</li> </ul>
<ul style="list-style-type: none"> <li>* Awareness of conventional acts, artifact and tool use.</li> <li>* Pride in knowing how to use objects.</li> <li>* Thumb-forefinger grasp effective.</li> </ul>	<ul style="list-style-type: none"> <li>* Continued learning of domestic ritual and social convention.</li> <li>* Will act out fragments of rituals (eating, drinking, using tools, friendly exchanges of objects).</li> </ul>
<ul style="list-style-type: none"> <li>* Mother makes more instructions and speaks in a more matter of fact tone.</li> <li>* Strong cultural effects act on mother.</li> <li>* Mother plays important role in the sharing of subjective states: is sensitive to state of infant (mood, direction of attention etc.) and will match her own to it (e.g. affect attunement).</li> <li>* Mother will give situations/objects affective reference (e.g. infant will look to mother to see if an event is happy etc.).</li> </ul>	<ul style="list-style-type: none"> <li>* Mother needs to give infant constant affectionate support; absence leads to speechless withdrawal.</li> <li>* Mother encourages language development.</li> <li>* Mother instructs infant in construction of verbal self (i.e. what society considers 'private').</li> </ul>

## Appendix IV. Questionnaire Given to Carers

- |                                  |                               |                                 |
|----------------------------------|-------------------------------|---------------------------------|
| 01. SEX:                         | 02. AGE:                      | 03. RESIDENCE:                  |
| 1. F                             | --                            | 1. hospital                     |
| 2. M                             |                               | 2. home                         |
| 04. ANTI-EPILEPTIC DRUGS:        | 05. PHENOBARBITONE:           | 06. BENZODRINE DRUGS:           |
| 1. two different drugs           | 1. two different drugs        | 1. two different drugs          |
| 2. high dose                     | 2. high dose                  | 2. high dose                    |
| 3. average dose                  | 3. average dose               | 3. average dose                 |
| 4. low dose                      | 4. low dose                   | 4. low dose                     |
| 5. none                          | 5. none                       | 5. none                         |
| 07. PSYCHIATRIC DRUGS:           | 08. EPILEPSY:                 | 09. SLEEP DISTURBANCE:          |
| 1. two different drugs           | 1. frequent/serious fits      | 1. very often disturbed sleep   |
| 2. high dose                     | 2. fits often                 | 2. often disturbed sleep        |
| 3. average dose                  | 3. occasional fits            | 3. occasional disturbed sleep   |
| 4. low dose                      | 4. fits rare                  | 4. rarely disturbed sleep       |
| 5. none                          | 5. not epileptic              | 5. never has disturbed sleep    |
| 10. MOBILITY:                    | 11. VISUAL HANDICAP:          | 12. AUDITORY HANDICAP:          |
| 1. cannot move                   | 1. blind                      | 1. deaf                         |
| 2. can move in chair             | 2. vision severely limited    | 2. hearing severely limited     |
| 3. can crawl                     | 3. partially blind            | 3. partially deaf               |
| 4. can walk with help            | 4. can see, with some problem | 4. some hearing problems        |
| 5. can walk unaided              | 5. can see                    | 5. can hear                     |
| 13. HEAD CONTROL:                | 14. VISUAL TRACKING:          | 15. HAND CONTROL:               |
| 1. no head control               | 1. no visual tracking         | 1. no use of hands              |
| 2. very little head control      | 2. severe problems            | 2. use severely restricted      |
| 3. some head control             | 3. some problems in tracking  | 3. use restricted               |
| 4. fairly good head control      | 4. fairly good tracking       | 4. slightly restricted use      |
| 5. good head control             | 5. good tracking              | 5. good hand control            |
| 16. STEREOTOPY:                  | 17. SELF-INJURY:              | 18. SELF HELP SKILLS:           |
| 1. no stereotopy                 | 1. none                       | 1. no skills                    |
| 2. rare                          | 2. rare                       | 2. very few skills              |
| 3. occasional                    | 3. occasional                 | 3. some skills                  |
| 4. often                         | 4. often                      | 4. most skills, with help       |
| 5. very often                    | 5. very often                 | 5. most skills, unaided         |
| 19. SPONTANEOUS LEARNING:        | 20. KNOWS CAUSE-EFFECT:       | 21. REFUSES CARERS INSTRUCTIONS |
| 1. no learning of routine etc.   | 1. never demonstrates         | 1. never refuses                |
| 2. rarely anticipates events     | 2. rarely demonstrates        | 2. rarely refuses               |
| 3. occasionally anticipates      | 3. occasionally demonstrates  | 3. occasionally refuses         |
| 4. often anticipates some events | 4. often demonstrates         | 4. often refuses                |
| 5. anticipates daily routine     | 5. very often demonstrates    | 5. very often refuses           |

## 22. ACTIVITY:

1. never active
2. rarely active
3. occasionally active
4. often active
5. very often active

## 25. ORIENTS TO PERSON:

1. never
2. rarely
3. occasionally
4. often
5. very often

## 28. INTEREST IN OBJECTS:

1. never
2. rarely
3. occasionally
4. often
5. very often

31. ACTS ON PERSON  
FOR EVENT:

1. never
2. rarely
3. occasionally
4. often
5. very often

## 34. EYE CONTACT:

1. never
2. rarely
3. occasionally
4. often
5. very often

## 37. MAKES SOUNDS:

1. never
2. rarely
3. occasionally
4. often
5. very often

## 40. USE OF YES/NO:

1. never
2. rarely
3. occasionally
4. often
5. very often

## 23. AWARENESS:

1. never aware
2. rarely aware
3. occasionally aware
4. often aware
5. very often aware

## 26. ORIENTS TO EVENT:

1. never
2. rarely
3. occasionally
4. often
5. very often

## 29. PUTS OBJECTS IN MOUTH:

1. never
2. rarely
3. occasionally
4. often
5. very often

## 32. INITIATES INTERACTION:

1. never
2. rarely
3. occasionally
4. often
5. very often

## 35. PHYSICAL CONTACT:

1. never likes it
2. rarely likes it but tolerates it
3. occasionally likes it
4. often likes it
5. very often likes & initiates it

## 38. VARIETY OF SOUNDS:

1. no sounds
2. one or two sounds
3. several sounds
4. many sounds
5. very many sounds/vocaliz..

## 41. TURNTAKING:

1. never
2. rarely
3. occasionally
4. often
5. very often

## 24. RESPONSIVENESS:

1. never responsive
2. rarely responsive
3. occasionally responsive
4. often responsive
5. very often responsive

## 27. ATTENTION SPAN:

1. never attends
2. span very short
3. span short
4. span fairly long
5. long attention span

30. RESPONSIVENESS TO  
INDIVIDUALS:

1. no people
2. one or two people
3. well known people only
4. all people
5. all people, esp. well known

## 33. SHUNS INTERACTION:

1. never
2. rarely
3. occasionally
4. often
5. very often

## 36. PROXIMITY:

1. far away
2. quite far away
3. no preference
4. close
5. very close

39. USE OF INAPPROPRIATE  
WORDS:

1. never
2. rarely
3. occasionally
4. often
5. very often

## 42. IMITATION:

1. never
2. rarely
3. occasionally
4. often
5. very often

43. USE OF EXPRESSIONS:

1. never
2. rarely
3. occasionally
4. often
5. very often

46. ANGRY EXPRESSIONS:

1. never
2. rarely
3. occasionally
4. often
5. very often

49. APPROPRIATE SMILING:

1. never
2. rarely
3. occasionally
4. often
5. very often

52. CRIES:

1. never
2. rarely
3. occasionally
4. often
5. very often

55. FEAR OF STRANGERS:

1. never
2. rarely
3. occasionally
4. often
5. very often

58. LAUGHTER AT EMOTIONAL OUTBURST:

1. never
2. rarely
3. occasionally
4. often
5. very often

61. EXPRESSES LIKING FOR PEOPLE:

1. none
2. mild
3. quite strong
4. strong
5. very strong

44. HAPPY EXPRESSIONS:

1. never
2. rarely
3. occasionally
4. often
5. very often

47. FEARFULL EXPRESSION:

1. never
2. rarely
3. occasionally
4. often
5. very often

50. INAPPROPRIATE LAUGHTER:

1. never
2. rarely
3. occasionally
4. often
5. very often

53. MOODS CHANGES:

1. never
2. rarely
3. occasionally
4. often
5. very often

56. FEAR OF STRANGE SITUATION:

1. never
2. rarely
3. occasionally
4. often
5. very often

59. LAUGHTER AT TEASING:

1. never
2. rarely
3. occasionally
4. often
5. very often

62. EXPRESSES LIKING FOR MUSIC:

1. none
2. mild
3. quite strong
4. strong
5. very strong

45. SAD EXPRESSIONS:

1. never
2. rarely
3. occasionally
4. often
5. very often

48. APPROPRIATE LAUGHTER:

1. never
2. rarely
3. occasionally
4. often
5. very often

51. INAPPROPRIATE SMILING:

1. never
2. rarely
3. occasionally
4. often
5. very often

54. MOOD EXPRESSION:

1. no difference in moods
2. few differences
3. some differences
4. large differences
5. dramatic differences

57. EMOTIONAL SENSITIVITY:

1. never sensitive to moods
2. rarely sensitive
3. occasionally sensitive
4. often sensitive
5. very often sensitive

60. RESPONSE TO ANGRY VOICE:

1. never
2. rarely
3. occasionally
4. often
5. very often

63. EXPRESSES LIKING FOR TRAVEL:

1. none
2. mild
3. quite strong
4. strong
5. very strong

## DECLARATION

This thesis was researched and written between October 1986 and September 1989. During this time I was employed as a research assistant on the 'Moving in Sympathy' project. The thesis is entirely separate from this project.

This declaration confirms that all work contained in this thesis is my own, and that I am responsible for it's composition.

Signed